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VOCATIONAL EXPERIENCES OF SURVIVORS OF SEVERE TBI WITH DIVERSE  
EMPLOYMENT PATTERNS: AN EXPLANATORY MIXED METHOD DESIGN

By

Erin J. Bush

A DISSERTATION

Presented to the Faculty of  
The Graduate College at the University of Nebraska  
In Partial Fulfillment of Requirements  
For the Degree of Doctor of Philosophy

Major: Interdepartmental Area of Human Sciences  
(Communication Disorders)

Under the Supervision of Professor Karen Hux

Lincoln, Nebraska

November, 2011

# VOCATIONAL EXPERIENCES OF SURVIVORS OF SEVERE TBI WITH DIVERSE EMPLOYMENT PATTERNS: AN EXPLANATORY MIXED METHOD DESIGN

Erin J. Bush, Ph.D.

University of Nebraska, 2011

Advisor: Karen Hux

Employment status is a salient outcome following traumatic brain injury (TBI). A return to productive activity relates in complex ways to quality of life, and loss of employment competence has potentially devastating effects on survivors. Currently, inadequate information exists about the distribution of occupations held by survivors, post-injury employment stability, and the frequency that survivors return to their pre-injury occupations. The research presented herein addressed these issues. This study consisted of two phases. Through Phase 1, the researcher gathered quantitative employment data regarding a pool of 283 survivors of severe TBI. She then conducted telephone interviews of family members of 20 survivors who had post-injury employment experiences, and obtained employment distribution data. Phase 2 consisted of qualitative data collection through in-depth interviews with 6 family members of a survivor of TBI, 5 survivors themselves, and 1 job supervisor of a survivor participant. The database search of 283 TBI survivors revealed that 156 (55%) returned either to paid or volunteer work positions immediately post-discharge. The researcher also obtained quantitative results from the 20 target participants. These distribution results detailed demographic and educational information, pre-injury and post-injury employment types, post-injury work statuses, survivor profiles, and post-injury employment success (PIES) scores. The researcher derived the latter two results from measures she developed for the purpose of this study. Phase 2 data included themes and subthemes derived from participant interview transcripts. The researcher used a multiple case study format to display the results, and then conducted a cross-case analysis of the 5 survivors and

gleaned from it cross-case themes. The 5 cross-case themes were (a) Challenges, (b) Strategies, (c) Work-related Issues, (d) Social and Personality Changes, and (e) Effect on the Family. After comparing Phase 1 and Phase 2 data sets, the researcher obtained mixed results regarding job satisfaction and employment success.

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## DEDICATION

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## **Introduction**

Approximately 1.7 million people sustain traumatic brain injuries (TBIs) annually. Of these, 80% receive emergency room care only, 16% receive at least some in-patient or out-patient medical or rehabilitation treatment, and 3% die (Faul, Xu, Wald, & Coronado, 2010). Researchers estimate that 5.3 million people are living with disabilities secondary to TBI in the United States alone (Thurman, Alverson, Dunn, Guerrero, & Sniezk, 1999), and most brain injury experts consider this estimate to be low, given that many survivors of TBI are never identified as such or do not seek treatment (Langlois, Rutland-Brown, & Wald, 2006).

The number of people who survive TBIs has grown in recent years due to medical and technological advances (Crisp, 1993; Leahy & Lam, 1998; Yasuda, Wehman, Targett, Cifu, & West, 2001; Leung & Man, 2005). In particular, the number of people surviving moderate to severe injuries has increased (Devitt, Colantonio, Dawson, Teare, Ratcliff, & Chase, 2006), resulting in a growing number of survivors who experience serious long-term problems. These problems occur in areas such as memory, attention, processing speed, social interaction, and emotional and behavioral responses (Crisp, 1993); other physical disabilities and common visual impairments can be problematic following brain injury as well. Langlois and colleagues (2006) estimated that 80,000 to 90,000 survivors each year experience some type of permanent functional loss or disability. According to one report, approximately one third of adults hospitalized with TBI still need help with daily activities one year after their discharge (Langlois et al., 2003).

Certain groups of people are at a higher risk for TBI than others due to gender, race and ethnicity, or age. In every race/ethnicity group (Langlois et al., 2003) and age group, males are more likely than females to sustain TBIs (Faul et al., 2010). In terms of race and ethnicity, black people have a 35% higher incidence rate than white people (Jager, Weiss, Coben, & Pepe, 2000). In a study by the Centers for Disease Control, Langlois and colleagues (2003) reported that hospital discharges after TBI are higher for American Indians, Alaska Natives, and Blacks than for any other racial group nationwide. More specifically, for people ages 20 to 44 years of age, American Indians and Alaska Natives have the highest hospital discharge rates due to TBI; for the age group of 0 to 4 year olds, Blacks have the highest rate; and for people older than 65 years, Whites have the highest rate of TBI-related discharges. The three age groups most likely to incur TBIs are children 0 to 4 years old, adolescents 15 to 19 years old, and adults 65 years and older (Faul et al., 2010). Hence, young people pursuing higher education goals or preparing to join the workforce constitute one of the highest risk groups for sustaining TBIs and are among the most frequent survivors. Over half (58%) of all TBI survivors are of working age (Langlois et al., 2006).

The relatively young age range at which many people sustain TBIs makes them particularly vulnerable to problems in the workplace. Even without brain injuries, young people often encounter challenges entering the workplace because of their immaturity and lack of work experience. Survivors of TBI contend with many obstacles that compound these already present challenges. Because of these concomitant factors, survivors attempting to enter or re-enter the workplace are often unsuccessful.

Unemployment figures for survivors range from 12% to 88% (Bushnik, Hanks, Kreutzer, & Rosenthal, 2003; McCrimmon, & Oddy, 2006; O'Neil et al., 1998; Shames, Treger, Ring, & Giaquinto, 2007; Tsaousides, Ashman, & Seter, 2008). Ben-Yishay and colleagues (1987) reported that survivors suffering moderate to severe injuries may have unemployment rates as high as 90%. This vast percentage range is likely attributable to differing research methods across studies on factors such as: (a) classifications used to indicate injury severity; (b) definitions of return to work (RTW) and work; (c) the variety of countries in which past studies took place and the compensation, benefits, and disincentives of RTW in those countries; and (d) inconsistent availability and use of vocational rehabilitation programs and support services (Shames et al., 2007). Regardless of these factors, researchers have established that young adult survivors of TBI who receive high school special education services work and attend higher education institutions at lower rates than their non-disabled peers (Wagner, Newman, Carneto, Garza, & Levine, 2005). Likewise, in a study of young adults who received special education in high school, TBI survivors were among the groups identified most frequently as needing vocational services, ranking second only to their counterparts with emotional disturbances (Todis & Glang, 2008).

Researchers often select employment status as a dependent variable in studies about rehabilitation outcomes for survivors of TBI (Wehman, Sherron, Kregel, Kreutzer, Tran, & Cifu, 1993), and many people consider the return to productive activity to be a rehabilitation milestone (Wagner, Hammond, Howell, & Wiercisiewski, 2002). In addition, many researchers have demonstrated that employment factors relate in complex

ways to other aspects affecting a survivor's quality of life (QOL), such as financial issues, social acceptance, and general well-being (e.g., Finset, Dyrnes, Krogstad, & Berstad, 1995; Johnstone, Mount, & Schopp, 2003; O'Neil et al., 1998). Certainly, a loss of employment competence can have a potentially devastating effect on a survivor's self-identity, independence, and emotional welfare (Prigatano, 1989). Lezak (1987) found that survivors of TBI evaluated during their first, second, and third years following injury consistently reported social contact, work/school status, and leisure activities as areas of greatest impairment, all of which have strong connections to RTW, social integration, and QOL (O'Neil et al., 1998). The potential a survivor has for post-injury employment affects the psychosocial adjustment of the individual, as well as his/her family, the discharge planning process, the search for rehabilitation services, and the utilization of vocational supports (Cattelani, Tanzi, Lombardi, & Mazzuchi, 2002).

Researchers have investigated various aspects of RTW following TBI. For example, past qualitative researchers have explored work adjustment and readjustment (Power & Hershenson, 2003), the influence of intrinsic and extrinsic factors on participation in productive activities (Petrella, McColl, Krupa, & Johnston, 2005), transition experiences from hospital to home (Turner et al., 2007), coping with community reintegration after brain injury (Karloviits & McColl, 1999), survivors' conceptualization on returning to work (Oppermann, 2004), survivors' definitions of success in the work place (Levack, McPherson, & McNaughton, 2004), and general aspects of survivors' experiences returning to work after brain injury (Crisp, 1993; Rubenson, Svensson, Linddahl, & Bjorklund, 2007). Quantitative researchers have

focused on topics such as return to work statistics (e.g., Olver, Ponsford, & Curran, 1996; Johnson, 1998; Johnstone et al., 2003; Fraser, Machamer, Temkin, Dikmen, & Doctor, 2006; Livingston, Tripp, Biggs, & Lavery, 2009), variables predicting survivors who are and are not likely to succeed in RTW or return to school endeavors (e.g. Ip, Dornan, & Schentag, 1995; O'Connell, 2000; Cattelani et al., 2002; Johnstone, Vessel, Bounds, Hoskins, & Sherman, 2003), and the effectiveness of different rehabilitation programs supporting survivors' re-employment (e.g., Ben-Yishay, Silver, Piasetsky, & Rattock, 1987; Ellerd & Moore, 1992; Possl, Jurgensmeyer, Karlbauer, Wenz, & Goldenberg, 2001). Through this research, professionals have identified numerous variables that may influence whether a survivor returns to work. Generally, these variables fall into one of five categories: (a) pre-injury demographics, (b) injury severity, (c) post-injury demographics, (d) neuropsychological outcomes, and (e) functional outcomes. An in-depth discussion of these variables appears in the following chapter.

Researchers have inadequately explored the distribution of types of occupations most commonly held by survivors, post-injury employment stability, factors influencing survivors' selection of jobs, and how frequently survivors return to occupations comparable to those in which they engaged prior to injury. Likewise, researchers have not yet investigated the reasons some survivors successfully regain and retain employment while others do not. The techniques and strategies used by survivors who are successful in maintaining stable employment following injury remains ambiguous.

## **Purpose**

The purpose of this research was to address the aforementioned issues by

exploring the employment experiences of survivors of severe TBI who have differing patterns of post-injury employment. The research design involved the use of a mixed method approach. The researcher first used quantitative procedures to examine occupational distribution data among a pool of survivors. The researcher then collected qualitative data through in-depth, semi-structured interviews of a subgroup of survivors, their family members or caregivers, and, when possible, their past or current employment supervisors.

The use of quantitative measures facilitated obtainment of distribution data regarding survivors' post injury (a) employment status, (b) employment stability, (c) number of jobs held, and (d) type(s) of employment. In contrast, qualitative data allowed for the understanding of each survivor from his or her own point of view. Having access to this qualitative information is important for rehabilitation professionals as they attempt to tailor strategies to fit an individual survivor's unique life circumstances (Kielhofner, Braveman, Baron, Fisher, Hammel, & Littleton, 1999). Likewise, Crisp (1993) suggested that qualitative research may be more appropriate than quantitative methods for investigating rehabilitation services because the resulting data relates to "specific social contexts that are of concern to these people (i.e., rehabilitation professionals, survivors, and survivors' advocates). It reports their perceptions of their social world, first hand" (p. 403).

Opperman (2004), noting the paucity of qualitative studies in this area of research, stated that the body of related quantitative studies lacks rich descriptions. Reports of individual cases can provide these descriptions. Specifically, data gathered through

interviews regarding employment factors can provide (a) insight into a worker's analysis of his/her own abilities and limitations, (b) information about the level of job commitment, (c) awareness of the consequences that the injury has had on non-work related roles, (d) insight into the ability to adjust behaviors and routines, and (e) the individual's perception of the work environment. Knowledge of these aspects is likely to facilitate rehabilitation professionals' identification of and attention to individuals' RTW barriers (Fisher, 1999). Roscigno and Van Liew (2008) also emphasized the need for qualitative research with survivors of TBI who have diverse social situations. An increase in this type of research would contribute to a more extensive conception of both the individual and the social factors that affect his/her life after injury. Furthermore, a qualitative approach to research may assist health care workers in the development of appropriate and caring intervention programs within survivors' own social contexts (Swanson, 1993).

People likely to benefit from information gleaned from this study include TBI survivors themselves; survivors' family members and caregivers; employers; policy makers; vocational rehabilitation administrators and staff; job coaches; post-secondary academic advisors, administrators, and staff working in offices for students with disabilities; and researchers in related fields.

## **Design**

The researcher used a mixed method explanatory sequential design to structure this project. Mixed method studies incorporate both quantitative and qualitative research questions, data collection, data analysis, and results into a single study or one with

multiple phases (Tashakkori & Teddlie, 2008). Together, the quantitative and qualitative data provide a more in-depth view of the issue than would be possible with only one type of data (Creswell & Clark, 2007). An explanatory sequential design is a two-phased study that begins with collecting quantitative data and, following analysis of the quantitative results, designates a finding that requires additional explanation. This additional explanation is sought through the analysis of qualitative data (Creswell & Clark, 2007).

Phase 1 of the current study involved quantitative data collection from close relatives or caregivers of survivors of severe TBI who have post-injury employment experiences. The researcher obtained demographic, injury, and employment history information about the survivors during this research phase. The researcher then conducted purposive sampling, utilizing principles of maximum diversity to identify Phase 2 participants from the quantitative participant population.

The researcher structured Phase 2 as a multiple case study. A multiple case study is a qualitative design in which the researcher selects one issue or concern on which to focus but uses multiple cases with which to illustrate the research question (Creswell, 2007). Phase 2 began with the collection of qualitative data about the employment experiences of the subgroup of survivors identified through the purposive sampling process. The researcher collected qualitative data by conducting interviews with the TBI survivors, a family member or caregiver associated with each survivor, and any available current or past job supervisors associated with the survivors. Figure 1 provides a visual diagram of the explanatory sequential design used to structure this research. The Institutional Review Board of the University of Nebraska - Lincoln granted approval to



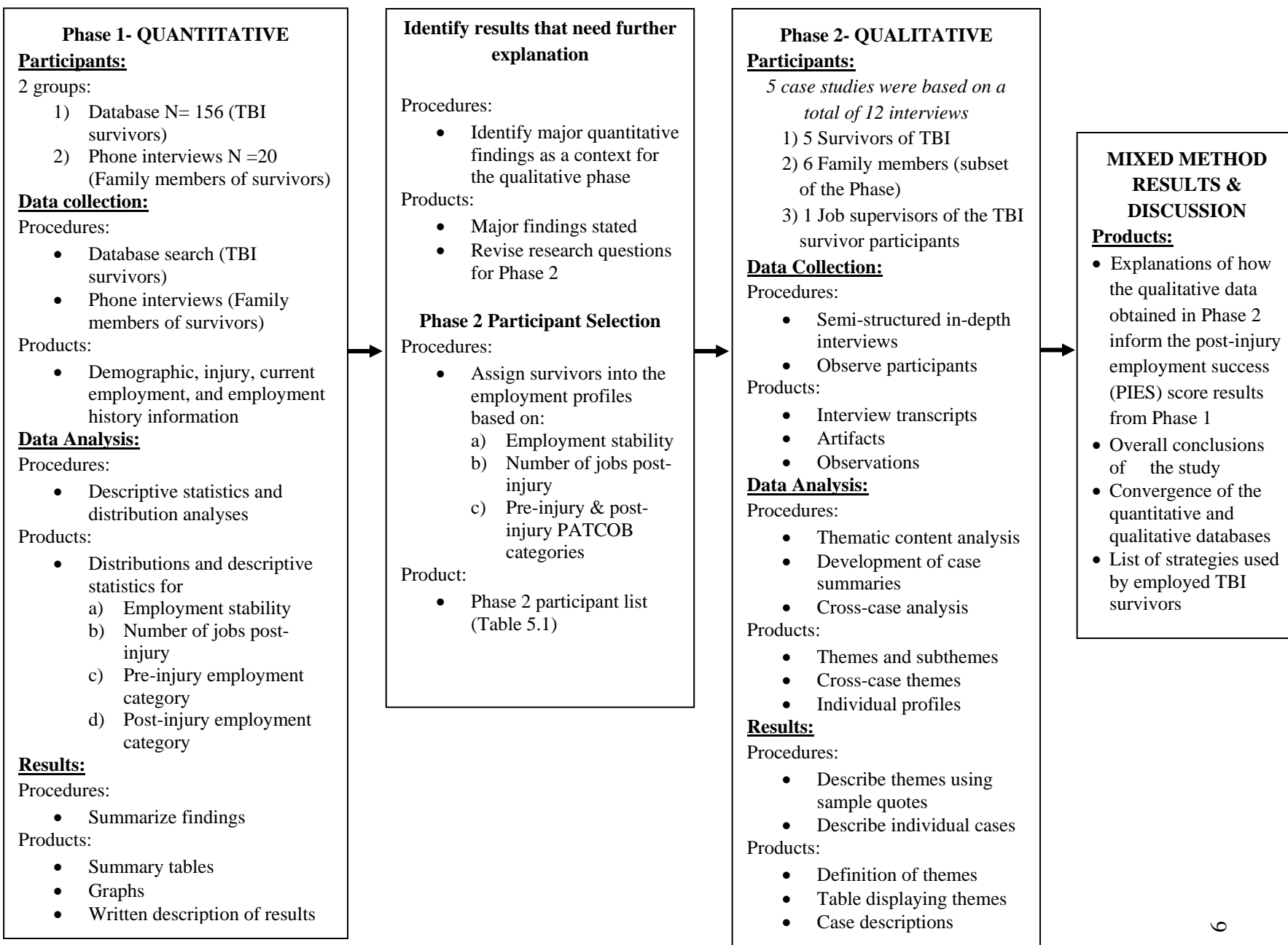


Figure 1-1. Visual Diagram

perform the research prior to the initiation of data collection.

### **Definition of Terms**

A **TBI** is an injury to the head that disrupts normal functioning in the brain (Faul, Xu, Wald, & Coronado, 2010). This injury may result from a jolt, bump, or blow to the head or by penetration of the skull by a foreign object. For the purpose of this study, TBI referred to any injury in which the brain incurred diffuse damage to multiple regions. The researcher included closed and open head injuries as forms of TBI but also included injuries caused by infections of the brain or the meninges surrounding the brain and injuries resulting from anoxia or hypoxia.

The researcher used the Equal Employment Opportunity Commission's (EEOC) established job categories known by the acronym of **PATCOB** (Travers, 1998) to classify the type(s) of employment a survivor previously or currently held. These work category delineations served to describe survivors' job types uniformly and are similar to those used in past research about TBI survivors. The EEOC classifications used for this study specify the following categories:

- **Professional Occupations (P)** including those that require 4 years or more of higher education with a degree in a specific area of study (e.g., engineering, medicine, accounting).
- **Administrative Occupations (A)** including those in the occupational fields of management or administration that require substantial levels of analysis, judgment, and responsibility (e.g., program manager, budget analyst). These positions do not require specialized educational majors.

- **Technical Occupations (T)** involving work associated with and supportive of a professional or administrative field that is non-routine in nature and requires extensive practical knowledge gained through on-the-job experience or specific training less than that represented by college graduation.
- **Clerical Occupations (C)** involving structured work in support of office, business, or fiscal operations that is performed in accordance with established policies, procedures, or techniques and that requires training, experience, or working knowledge related to the tasks performed.
- **Other White Collar Occupations (O)** involving other employed positions not related to the Professional, Administrative, Technical, Clerical, or Blue Collar occupational categories. Predominant occupations in this category are fire prevention, police officers, and correctional jobs.
- **Blue Collar Occupations (B)** involving the performance of a recognized trade, craft, or manual labor (unskilled, semi-skilled, or skilled) and typically associated with a Wage Grade or Union (e.g., plumber, heavy equipment operator, truck driver).

The researcher designated the term **employment profile** to describe a survivor's pre-injury job classification and post-injury employment stability as well as number of jobs held. As shown in Table 1-1, a total of twelve possible employment profiles reflected a survivor's (a) post-injury employment stability, (b) number of post-injury jobs, and (c) pre-injury PATCOB work category. For simplification purposes and because of some overlap of employment duties across categories, the researcher combined P and A jobs, T and C jobs, and O and B jobs within the PATCOB system.

Thus, the abbreviations for the twelve possible profiles are SFPA, SFTC, SFOB, SMPA, SMTc, SMOB, UFPA, UFTC, UTOB, UMPA, UMTc, and UMOB.

The researcher used the term **post-injury employment success score** to quantify a survivor's current employment status. The researcher calculated this score based on a survivor's employment stability, number of jobs post-injury, current or most recent PATCOB employment category, and number of hours currently worked weekly.

Assignment of point values to the possible subcategories associated with each of these factors appears in Table 1-2. Post-injury employment success scores ranged from 3 to 10 and were the sum of numbers assigned for a given survivor.

Table 1-1

*Definitions of Terms associated with Employment Profiles*

Post-injury employment stability	Number of post-injury jobs	Pre-injury PATCOB category
<b>S (stable)</b> = held at least one job for greater than one year	<b>F (few)</b> = 1-2 jobs	<b>PA</b> = Professional or Administrative
<b>U (unstable)</b> = no job held for greater than one year	<b>M (many)</b> = > 2 jobs	<b>TC</b> = Technical or Clerical
		<b>OB</b> = Other White Collar or Blue Collar

## Research Questions

### Phase 1 Questions - Quantitative

The researcher sought to answer the following questions through the quantitative portion of this study:

1. What is the distribution of TBI survivor participants regarding:

Table 1-2

*Point Value Assignments for Determining Post-injury Employment Success Scores*

Employment stability	Number of jobs	PATCOB category	Weekly hours
S (stable) = 2	F (few) = 2	PA = 3	More than 30 = 3
U (unstable) = 1	M (many) = 1	TC = 2	21- 30 = 2
		OB = 1	Less than 20 = 1
			Unemployed = 0

- (a) Employment status
  - (b) Employment stability?
  - (c) Number of jobs post-injury?
  - (d) Pre-injury employment categories (PATCOB)?
2. What is the distribution of TBI survivor participants regarding their most recent or current employment category (PATCOB)?
3. What is the distribution of TBI survivor participants across the various combinations of 12 employment profiles developed by the researcher?
4. What is the post-injury employment success score for each TBI survivor participant based on his/her:
  - (a) Employment stability?
  - (b) Number of jobs post-injury?
  - (c) PATCOB category of the current or most recent job held?
  - (d) Number of hours currently worked per week?

**Phase 2 Questions - Qualitative**

The central question structuring the qualitative phase of the research was:

1. How do TBI survivor participants and the people associated with them describe their post-injury employment experiences?
  - (a) How do TBI survivor participants and the people associated with them describe the survivor's on-going challenges and strengths regarding employment?
  - (b) What are the strategies used by TBI survivor participants to promote employment success?
  - (c) What are the themes identified in each case?
  - (d) What are the cross-case themes?

### **Mixed Method Question**

The mixed method question served to merge the quantitative and qualitative findings. It was:

How do the qualitative data obtained in Phase 2 inform the post-injury employment success score results from Phase 1?

## CHAPTER 2

### Literature review

#### Work

People's conception of *work* is often an employment opportunity for which one receives payment; however, *work* can also include unpaid activities such as housework, child rearing, and volunteerism (Haworth, & Lewis, 2005). One means of encouraging a broad definition of *work* is to distinguish between competitive or paid work and non-competitive or unpaid work. Using this terminology, volunteer work is a type of non-competitive work. It is a chosen activity for which one does not receive payment but that requires social skills and confidence and may result in the attainment of intrinsic rewards. As such, volunteer work shares many qualities with paid work, including its cost-reward nature and level of commitment (Stebbins, 2004). For the purpose of this study, *work* refers to both paid employment and participation in volunteer activities.

One reason people work is to attain rewards, both intrinsic rewards—such as socialization, self esteem, and a sense of purpose—and extrinsic rewards—such as payment, medical insurance, and/or other health benefits. Researchers from Great Britain demonstrated that unemployed people have lower levels of well-being than those who work despite the receipt of government financial aid (Clark & Oswald, 1994). Unemployed individuals fare worse in terms of well-being than those who are experiencing marital separation or going through divorce. Despite gender, occupation, tenure, prior performance, or amount of supervisor support, the more advantageous

workers viewed their benefit package; thus, the more supportive they were of their employment institution (Lambert, 2000).

The Gallup Organization collected data for a worldwide study on wealth and happiness in 2005 and 2006 (Diener, Ng, Harter, & Arora, 2010). They surveyed a representative population of people, fifteen years and older, from 132 countries accounting for 96% of the world's population. After weighting the 136,839 respondent-samples within each nation to represent demographic proportions accurately within the individual societies, the researchers found that income had a strong, positive association with workers' evaluations of their well-being. The researchers purported that this outcome may have societal influences because they found that national income predicted life evaluations as well, even after controlling for individual income. Results of this study also supported the notion that the relation between life evaluation and well-being corresponds with the attainment of material goals. Although the researchers acknowledged that people need more than just money to experience quality of life, increased income is strongly associated with positive life evaluation and relates significantly to positive feelings (Diener et al., 2010). Using the same Gallup Organization data, Deaton (2008) sought to understand the relation between income and life satisfaction. He found similar results to Diener and colleagues (2010) in that a positive relation exists between life satisfaction and national income. Despite the fact that most people need to work to earn a living, researchers have found that people also work for enjoyment (Csikszentmihalyi & LeFevre, 1989). Working is a source of considerable satisfaction for many people. Even though people may assume that engagement in leisure



activities provides greater enjoyment than engagement in work tasks, the opposite may actually be true. To investigate this notion, Csikszentmihalyi and LeFevre (1989) performed a study about the frequency with which managers, blue collar workers, and clerical workers experienced positive feelings about work and leisure activities. The researchers found that the majority of leisure time activities did not make people feel happy or strong. Instead, participants' most positive experiences stemmed from the performance of work tasks. The researchers purported that the obligatory nature of work may mask its enjoyment. Additionally, they speculated that people might find leisure activities with considerable built-in structure (i.e., team sports or planned group activities) more enjoyable than unstructured leisure activities.

Individuals challenged by their work reap the benefits of improved self-esteem and mental flexibility (Kohn & Schooler, 1983). Additionally, work provides people with structure, opportunities for contact with others, self-esteem, and the capacity to achieve status (Applebaum, 1992). Researchers have discovered that creative activities both in work and leisure time provide optimal experiences.

### **The Model of Human Occupation**

The Model of Human Occupation (MOHO) is a conceptual framework consisting of four factors—volition, habituation, performance, and environment—that either support or detract from work success (Kielhofner, Braveman, Baron, Fisher, Hammel, & Littleton, 1999). Kielhofner and colleagues devised the model to explain the activities with which people fill their lives. Following is a description of how the four main aspects of the model affect work behavior.

The component of volition within the MOHO refers to a collection of ideas and feelings a worker holds about his/her abilities and effectiveness, elements promoting his/her happiness at work, and job factors believed to be important and meaningful. According to Kielhofner and colleagues (1999), these values and interests influence what people do and how they choose to behave, thus leading to the second factor of habituation. Habituation is the collective processes in everyday life that form a pattern of regularity. Habituation processes include internalized roles and habits that give regularity to work behavior and evolve from repeated actions in a certain environment. They enable occupational behavior to become automatic and to suit individual environments. The third factor of the MOHO, performance, refers to one's inherent capabilities. These capabilities interact with impairments that confine performance and sometimes prevent a person from engaging in necessary work behaviors. Finally, the MOHO factor of environment influences both social and physical components of work success.

Environment refers to one's physical space and objects used for work as well as the type of work performed and the resulting social groups. The MOHO purports that all work behavior is a result of the interrelation of volition, habituation, performance, and environment (Kielhofner et al., 1999).

**MOHO and the Disabled Worker.** Rehabilitation therapists in general have found the MOHO helpful for exploring and identifying factors influencing job success. Though researchers have used this model for many different populations, it is particularly useful when focusing on individuals within a single disability category, such as people with TBI (Kielhofner et al., 1999; Depoy, 1990). Typically, a single component cannot

sufficiently account for work failure or success, although the tendency has been for researchers to focus mistakenly on only performance factors when considering the employment experiences of people with disabilities. Instead, understanding how a person performs and experiences work requires the examination of all four factors. Adequate job performance in isolation is insufficient for successfully adapting to a given occupation; adequate volition, habituation, and environmental factors must also be present for job success to occur. As such, the MOHO provides an all-inclusive framework for understanding individuals' occupational experiences and offers a holistic and effective means of examining individual aspects of a disabled worker's development and incorporation of rehabilitation strategies and work-related support services. The model can assist therapists in articulating and documenting psychosocial aspects of an individual's situation as well as providing a means of thoroughly evaluating and planning individual treatment plans. For the current study, the model supplies a framework for formulating interview protocols to obtain a comprehensive view of each survivor's work experiences, successes, challenges, and struggles following acquired brain injury.

### **TBI and Financial Burdens**

Not only does financial dependence on others often occur following injury, but treatment for an injury itself raises serious financial issues. In 1999 in the United States, acute medical care and rehabilitation costs were as high as 6 billion dollars, and indirect costs, such as lost wages and productivity and long-term health care, were as much as 22 billion dollars annually (Yasuda, Wehman, Targett, Cifu, & West, 2001). The per person costs of hospitalization following different severities of TBI averaged \$8,189 for

moderate injuries, \$14,603 for serious injuries, \$16,788 for severe injuries, and \$33,537 for critical injuries. However, the cost of hospitalization also varied by the type of injury incurred. Hospitalization costs in 1999 for the average TBI associated with a gunshot wound was \$20,084; costs associated with motor vehicle accidents were slightly higher at \$20,522 per person; and hospitalization costs for blows to the head and falls were somewhat less at \$19,949 and \$15,860, respectively (McGarry, Thompson, Millham, Cowell, Snyder, Lenderking, & Weinstein, 2002).

In contrast to the enormity of medical costs associated with the treatment of moderate and severe brain injuries, researchers have concluded that lost productivity may be the largest component of economic cost associated with mild brain injuries (Fife, 1987; Max, McKenzie, & Rice, 1991). Mild TBI accounts for approximately 150,000 hospitalizations each year in the United States and nearly 500,000 emergency room visits without hospital admission (Boake, McCauley, Pedroza, Levin, Brown, & Brundage, 2005). In general, patients hospitalized with mild TBI do not work for 1 to 3 months after injury (Boake et al., 2005; Dikmen, Temkin, Machamer, Holubkov, Fraser, & Winn, 1994). Figures regarding survivors of mild TBI are difficult to confirm (Boake et al., 2005), however, because many mild injuries are unverified, self-reported injuries (Fife, 1987; Vanderploeg, Curtiss, Duchnik, & Lewis, 2003) or are injuries for which an individual is never hospitalized (Coonley-Hoganson, Sachs, Desai, & Whitman, 1984). These challenges make the cause of lost productivity following mild TBI difficult to assign. Some of the many contributing factors include: (a) the length of absence from work following injury; (b) the type and severity of injury; (c) work absences after initial

return-to-work because of on-going health problems; and (d) discrepancies between pre-injury and post-injury job status (Boake et al., 2005).

Survivors' successful return to employment benefits society by reducing an economic burden created by the vast number of TBIs suffered each year. (Machamer, Temkin, Fraser, Doctor, & Dikmen, 2005). The estimated cost of TBI in 1985 totaled approximately \$37 billion per year (Max et. 1991). One can assume that the total cost is much greater today.

### **Return to Work Following TBI**

The topic of return to work following TBI has received considerable research attention over the past two decades. Some researchers—such as Ruff and colleagues (1993)—have focused on survivors' early return to work experiences, whereas others—such as Brooks, McKinlay, Symington, Beattie, and Campsie (1987) and Olver and colleagues (1996)—have examined survivors' experiences many years post-injury; still other researchers—such as Franulic, Carbonell, Pinto, & Sepulveda (2004)—have examined multiple time periods following injury. Despite differences among timeframes, findings of all of these researchers have established that returning to work following TBI is a frustrating and difficult process more often than not.

Regardless of the associated challenges, obtaining employment can enhance recovery as well as quality of life (QOL) for survivors of TBI. Among other benefits, it provides motivation to leave the house daily and enhances financial independence and the attainment of benefits (Wehman, Targett, West, & Kregel, 2005). It also increases the likelihood a survivor will make new friends or re-connect with old ones (West, 1995) and

can enhance self-esteem (Barnes, 1999). Further, Kreutzer, Doherty, Harris, and Zasler (1999) contend that acquisition of productive work corresponds with decreased physical disability, substance abuse, and other challenges often experienced secondary to brain injury.

**Return to Work Statistics.** The high prevalence of unemployment post-TBI creates devastating economic problems. Over 20 years ago, researchers found that 70% of persons with TBI were unemployed at 5 years post-injury despite the fact that 86% of them had jobs prior to their injury; of those employed post-injury, only 18% were working full-time, compared to 52% prior to injury (Brooks, McKinlay, Symington, Beattie, & Campsie, 1987). Doctor and colleagues (Doctor, Castro, Temkin, Fraser, Machamer, & Dikmen, 2005) examined the risk of unemployment for survivors of TBI after controlling for demographic characteristics known to associate closely with employment status (e.g., age, race, etc.). The researchers determined that even after adjusting for general population risks, survivors of TBI are at a considerably higher risk for unemployment than their non-injured peers.

Unemployment figures vary, however, based on the length of time between injury and research participation, severity of injury, and the researcher's definition of employment (see Table 2-1). For example, Ruff and colleagues (1993) studied a sample consisting only of survivors of severe TBI. The study included two cohorts, one of whom the researchers evaluated at 6 months post-injury and the other of whom they evaluated at 12 months post-injury. In the 6 month-cohort, 18% of those formerly employed had returned to work; in the 12 month cohort, 31% had returned to work. The authors noted

that multiple factors might have inflated the figures relating to survivors in the 12-month post-injury cohort. First, depression appears to be an inconsequential factor for survivors until at least 6 months post-injury. With the inception of depression or with a greater duration of depression, the likelihood increases that the mood disorder will negatively affect employment status. Second, employers may exercise more tolerance early on in a survivor's recovery because of the impressive progress made since injury. This may contribute to the expectation that the survivor will continue to make further improvements. When this does not come to fruition, the survivor's employment continuation may be at risk. In addition, follow-up longer than one year post-injury may reveal persistent psychosocial difficulties that jeopardize the retention of employment by survivors of TBI.

Table 2-1

*Percentage of Survivors who Returned to Work*

Authors	Year	Participant severity	Time interval	% employed pre-injury	% employed post-injury	Country
Levin & Grossman	1978	Severe	1 year post-injury	96%	22%	United States
Brooks, McKinlay, Symington, Beattie, & Campsie	1987	Severe	Between 2 and 7 years post-TBI	86% (52% full-time)	29% (18% full-time)	United Kingdom
Prigatano, Klonoff, & Bailey	1987	Severe	2-4 years post-TBI	Not given	23%	United States
Ruff,	1993	Severe	6 months	Not given	6 month	United

Marshall, Crouch, Klauber, Levin, Barth, Kreutzer, et al.			12 months Post-injury		cohort 18%; 12 month cohort 31%	States
Ip, Dornan, & Schentag	1995	Mixed (not significant)	1 year 3 years 5 years	100% working or in school	Returned to work or school: 43% (1 year); 50% (3 years); 67% (5 years)	Canada
Johnson	1987	Severe	Mean 3.5 years	100%	38%	Great Britain
Gollaher, High, Sherer, Bergloff, Boake, Young, & Ivanhoe	1998	Mixed	Between 1-3 years post- injury	88%	36%	United States
O'Connell	2000	Not given	One year post- rehabilitation	75%	42%	United States
Dikmen, Machamer, Powell, & Temkin	2003	Not given	3-5 years post-injury	18%	42%	United States
Johnstone, Mount, & Schopp	2003	Not given	One year post-injury	69% employed 11% students	31% employed 6% students	United States
Livingston, Tripp, Biggs, & Lavery	2009	Severe	Less than 3 years	76% in school or working full time	49% working or in school	United States



Recently, Dikmen and his colleagues (2003) reported that unemployment figures for survivors three to five years post-injury rose from 18% pre-injury to 42% post-injury. In a study of persons with new TBIs from a national database at one year post-injury, Johnstone and colleagues (2003) reported that employment rates fell from 69% pre-injury to 31% post-injury, that the average income, per month, declined by 51%, and that the mean amount of public assistance utilized by survivors increased by 275%. As such, from the time of injury to a one-year follow-up, the average total public assistance received increased from \$153 to \$421 every month.

Prigatano and colleagues (Prigatano, Klonoff, and Bailey, 1987) found that only 23% of persons who had GCS scores of 8 or less upon admission to a neurological institution gained employment between 2 and 4 years after injury. Furthermore, Dikmen and colleagues (2003) reported that of the 210 participants included in their study three to five years following a moderate to severe injury, 8% lived in a restricted environment (e.g., nursing home or group home) and one-third of the survivors could not be left alone for 24 hours or more; accordingly, 25% were completely financially dependent on others.

Livingston and colleagues (2009) studied a more recent sample of survivors of mild, moderate, or severe TBI. The researchers found that 76% of their sample was employed or attending school prior to injury. At three years' post-injury, 49% were back to work or attending school. However, of the survivors who had incurred severe injuries, only 38% had returned to work or school. Thus, the researchers concluded that survivors of severe TBI fare worse with obtaining employment or educational endeavors than those with mild to moderate injuries.

**Work Stability.** Not only is obtaining employment and re-entering the workforce challenging, but also job retention is a problem with which survivors must contend. Olver and colleagues (1996) found that 32% of survivors employed at two years post-injury did not have employment at 5 years post-injury. Johnson (1998) conducted a follow-up study with 64 survivors of severe TBI who were at least 10 years post-injury and who he had previously studied at 3 years post-injury (Johnson, 1987). Of the total, 42% had attempted to re-enter the workforce, with 20% of them having an irregular pattern of work and the remainder being unsuccessful in attaining work. Few changes were evident in the survivors' patterns of employment compared to the original data collected seven years earlier; that is, survivors tended to maintain the same employment status at 10 years post-injury that they had at 18 months to 2 years post-injury. Likewise, Johnstone and colleagues (1999) determined that, of the survivors who find employment, 75% become unemployed by the end of their first three months on the job.

Kreutzer and his colleagues (2003) conducted the first longitudinal study of employment stability following TBI. They studied 186 adults with TBI at one, two, and either three or four years post-injury. The researchers found that 34% of the individuals had employment at the time of all follow-up periods; an additional 34% demonstrated a pattern of unstable employment, meaning they were employed at one or two of the three follow-ups. Thirty nine percent of the participants were unemployed at the time of all follow-ups. These researchers also found that the number of employed survivors increased as time post-injury increased; that is, the more time that went by, the more likely it was that a survivor would obtain employment. Specifically, at one-year post-

injury, 35% of the survivor participants had employment; this increased to 42% at three years post-injury. The researchers did not collect information about whether the survivors returned to their previous employment or changed employment after injury.

Machamer and colleagues (2005) followed survivors of varying severity levels for 3 to 5 years post-injury. These researchers defined work stability by the amount of time worked (i.e., amount of time worked divided by time observed post-injury) and the occurrence of uninterrupted employment status once a survivor returned to work. They found that once survivors returned to work, their ability to maintain employment depended on pre-injury characteristics such as increased age, higher income prior to injury, or a pre-injury job with health benefits.

The implementation of supported employment has been wide-spread to combat job retention problems and to assist in transitioning survivors back into work settings (e.g., Ellerd, & Moore, 1992; O'Connell, 2000; Johnstone et al., 2003). However, in a study of 24 survivors of TBI who were involved in supported employment, researchers found a 71% employment rate at 12 months post injury, and only 38% were employed at 30 months post-injury (Ellerd & Moore, 1992). The most frequent reason cited for job loss, at both 12 and 30 months, was alcohol and substance abuse.

**Work Types.** Boake and colleagues (2005) studied 210 survivors of TBI of whom 90% suffered mild injuries and 10% suffered moderate injuries. The researchers found the following percents of survivors fitting into each of six post-injury job category: professional and technical – 12%; managerial, clerical, and sales – 14%; skilled laborer – 6%; semiskilled laborer – 33%; unskilled laborer – 19%; and unemployed – 16%. The

researchers did not provide information about the participants' job category distribution prior to injury.

Multiple researchers (e.g., Boake et al., 2005; Dikmen, Temkin, Machamer, Holubkov, Fraser, & Winn, 1994; MacKenzie, Morris, Jurkovich, Yasui, Cushing, Burgess, deLateur, McAndrew, & Swjontkowski., 1998) have found that higher pre-injury job status sometimes serves as a protective factor regarding post-injury work status, thus providing evidence opposing the view that survivors struggle more to maintain cognitively-demanding than less-demanding jobs following brain injury. This means that those survivors with pre-injury careers demanding use of higher cognitive skills had more job security post-injury than those with less cognitively-demanding pre-injury careers. Boake and colleagues (2005) speculated that this might be because greater flexibility exists in careers with high cognitive demands regarding both work schedule and work responsibilities.

**The Return to Work Process.** Some survivors return to the jobs they held before their injury, while others attain new employment, and still others experience extreme difficulty attaining and maintaining any type of employment. Of those returning to work following a mild injury, 79% returned to the same jobs and the same type of work they had done previous to injury; however, they often reported difficulties not experienced prior to injury. Of those who did not return to the same job or type of work, 44% reported that the reason for the change related to their injury. Twenty-six percent reported having problems either with the type or the amount of work and with interactions with others (Boake et al., 2005).

Leung and Man (2005), through descriptive analyses, determined that survivors who returned to their pre-injury job (mean age = 40.6) and those who changed occupations (mean age = 38.3) were substantially younger than unemployed survivors (mean age = 45.3). Notably, 70% of survivors whose pre-morbid jobs required a medium to heavy activity level could not return to the job and were unemployed at follow-up despite having participated in rehabilitation. Reduced productivity after returning to work is frequent among the general population of injured workers (Boake et al., 2005).

### **Persistent Challenges of TBI Survivors Affecting Return to Work**

Persistent cognitive, physical, and social-emotional challenges that people with TBIs experience make returning to work particularly difficult (Gary et al., 2009; Simpson & Schmitter-Edgecombe, 2002; Tsaousides, Warhowsky, Ashman, Cantor, Spielman, & Gordon, 2009). Brain injuries often result in challenges affecting vocational performance as well as the success of survivors in avocational endeavors (Ashman, Gordon, Cantor, & Hibbard, 2006).

**Cognitive Challenges.** Aspects of cognition such as attention, memory, and executive functions are among the consequences repeatedly reported as most problematic following brain injury (Carney & Schoenbrodt, 1994; Bashore & Ridderinkhof, 2002; Ylvisaker et al., 2005; Himanen et al., 2009). A strong relation exists between occupational functioning and cognitive functioning. As such, workers with jobs requiring high cognitive functioning earn more than workers with jobs requiring cognitive performance at lower levels (Gamboa, Holland, Tierney, & Gibson, 2006). For TBI survivors who have persistent cognitive deficits, lost earnings and lowered worklife

expectancy are common, and their earning potential changes in accordance with the type of work they can perform (Gamboa et al., 2006).

According to Gamboa and colleagues, cognitive disabilities exist “when a person has a condition lasting 6 months or more that results in difficulty learning, remembering, or concentrating” (2006, p. 327). Survivors of TBI may experience impairments with multiple aspects of cognition (Marschark, Richtsmeier, Richardson, Crovitz, & Henry, 2000). Attention, memory, learning new information, and executive functioning are particularly vulnerable, and deficits in these areas can directly affect TBI survivors re-entering the workforce. The fact that many of these deficits are not readily apparent during the initial stages of job attainment or by people unfamiliar with the survivor makes awareness of these potential challenges even more important.

***Attention and memory.*** Attention problems and the reduced capacity for information processing are frequently reported issues secondary to TBI (Bashore & Ridderinkhof, 2002). Memory problems following TBI are often the most common as well as the most unrelenting of survivors’ challenges (West, 1995). Attention and memory relate to one another in that arousal, the most basic form of attention, is also the most basic form of memory (Mateer & Sira, 2006). In other words, arousal must exist both to attend to something and to remember it. Thus, impairments of attention and memory are difficult to discuss separately. Attention is a multifaceted aspect of cognition, generally divided into multiple components. From most basic to most complex, these components include: arousal, sustained attention, working memory, selective attention, and alternating attention (Mateer & Sira, 2006).

Memory systems incorporate three important functions: input, storage, and retrieval (Wright & Limond, 2004). Input involves the intake or learning of information; storage refers to the preservation of information; and retrieval is the process of accessing the information when one needs it. Memory, particularly working memory, is impaired following a TBI (Ylvisaker & Feeney, 1998). Those with working memory deficits often have problems with real-world tasks because they have difficulty managing more than one undertaking at a time (Grafman, Sirigu, Spector, & Hendler, 1993). These deficits make employment particularly challenging. When researchers asked a group of survivors if they experienced problems with memory or concentration at work, 46% responded positively (Boake et al., 2005). Brain injury affects attention similarly. The component of attention most frequently impaired is that of executive attention control processes (Shallice, 1988), making many employment responsibilities, especially those requiring upper level cognitive skills, difficult.

***New learning.*** Another common challenge associated with TBI is difficulty mastering new information despite relatively successful reacquisition of previously learned material (Ylvisaker et al., 2001). This phenomenon may contribute to misperceptions by survivors, family members, and employers regarding a survivor's abilities with regard to vocational pursuits. This is especially true when injuries occur in late adolescence and adulthood, because survivors of this age already have a wealth of previously mastered information. The rapid reacquisition of previously mastered material may mislead people into believing that all learning will be comparable to that experienced prior to injury or during the early stages of recovery. In actuality, mastering

new material tends to be quite problematic for a majority of survivors of severe TBI (Ylvisaker et al., 2001). New learning also presents particular complications in the workplace, especially if the survivor returns to his/her pre-injury job following recovery. Familiar employers and co-workers may have particular difficulty understanding and accepting the challenges the survivor faces with regard to attaining novel information.

***Executive functions.*** Executive function is a comprehensive term describing many high-level cognitive processes. Cicerone and colleagues (2000) defined executive functioning as

...integrative cognitive processes that determine goal-directed and purposeful behavior and are superordinate in the orderly execution of daily life functions includ[ing]: the ability to formulate goals; to initiate behavior; to anticipate the consequences of actions; to plan and organize behavior according to the spatial, temporal, topical, or logical sequences; and to monitor and adapt behavior to fit a particular task or context (p. 1605).

Executive functioning includes many aspects of cognition such as initiating, goal-setting, planning, organizing, problem solving, using judgment, and self-monitoring (Mateer & Sira, 2006). Problems with executive functions can be the most disabling of all cognitive deficits, because they affect all facets of a person's functioning both professionally and personally (Tsaousides & Gordon, 2009).

**Psychosocial, emotional, and behavioral challenges.** Many individuals surviving brain injury experience social, emotional, and behavioral changes such as emotional lability, impulsivity, poor social judgment, indifference to other people's



emotions, and socially-impaired communication (Kendall & Terry, 1996; Morton & Wehman, 1995). One of the most agreed-upon behavioral problems following TBI relates to the changes a survivor experiences with his/her mood or emotions (Wiltol, Sander, Seel, & Kreutzer, 1996). These challenges can contribute to the struggles survivors experience when they attempt to return to work (Wiltol et al., 1996; Ownsworth & McKenna, 2004) or maintain close, personal relationships (Kendall & Terry, 1996). Even many years after injury, family members report that a survivor's behavioral changes can be more of a burden than any other persistent physical or cognitive deficits (Koskinen, 1998).

Social challenges create considerable problems for survivors of TBI (Fraas & Balz, 2008). Researchers have shown that developing close friendships and socializing with others is a greater challenge for survivors of TBI than for non-disabled individuals or for survivors of spinal cord injury (Brown & Vandergoot 1998). Further, by investigating adult survivors five years post-injury, Sand O'Brien (1998) found greater acceptance of their physical challenges than the challenges they experienced regarding the formation and maintenance of social and personal relationships.

In addition to the aforementioned deficits, adult survivors of brain injury have high incidences of depression, social isolation, and decreased quality of life (Fraas & Balz, 2008). Research indicates that between 15% and 42% of adults with TBI experience depression (Glenn et al., 2004), with the prevalence increasing after the first year post-injury (Fleminger et al., 2003). Other researchers have reported depressive symptoms in as many as 77% of TBI survivors, although many of these people do not

consider themselves depressed (Kreutzer et al., 2001). Some researchers have speculated that the feelings of isolation experienced by many survivors may be attributable to their inability to communicate successfully and efficiently with others (Galski Tompkins, & Johnston, 1998). The social and behavioral changes experienced by a survivor likely contribute to negative school, work, social, and family outcomes more so than any medical, physical, or cognitive effects. Irresponsible work habits and irritating behavior make supervising or working with a person with TBI extremely challenging (Ylvisaker & Feeney, 1998).

### **Predictor Variables**

Predictor variables affecting post-injury employability are numerous and complexly interrelated (Cattelani, Tanzi, Lombardi, & Mazzuchi, 2002; Shames et al., 2007). Researchers have identified numerous variables that may influence whether a survivor returns to work. For explanation purposes, these variables comprise four general categories: pre-injury demographic variables, injury severity variables, post-injury demographic variables, and outcome variables. Originally, the researcher identified 46 studies as including predictor variables for return to work (RTW) or return to productive activity (RTPA). After eliminating review articles, meta-analyses, intervention studies, or reports more than 15 years old, 22 studies remained. Review of the findings presented in these 22 empirical studies allowed identification of the most salient and pertinent predictor variables. Tables 2-2 through 2-5 provide overviews of the studies addressing one or more of the four types of targeted variables.

**Pre-injury demographic variables.** Twenty of the 22 research groups authoring manuscripts included in this review addressed at least one pre-injury demographic variable. Pre-injury demographic variables researchers have studied include: previous occupation or occupational stability, age when injured, gender/sex, marital status, level of education, race/ethnicity, social or behavior problems, and co-occurring disabilities (see Table 2-2).

The authors of 12 studies included previous occupation as an investigated predictor variable. Eight of these research groups (Boake et al., 2005; Felmingham, Baguley, & Crooks, 2001; Fleming, Tooth, Hassell, & Chan, 1999; Gollaher et al., 1998; Keyser-Marcus et al., 2002; MacKenzie et al., 1998; Sherer, Sander, Nick, High, Malec, & Rosenthal, 2002; Simpson, & Schmitter-Edgecombe, 2002) found the occupation a person held prior to injury was predictive of returning to work or productive activity post-injury. These researchers found that survivors with higher occupational levels before injury were more likely to obtain employment after injury. Findings reported in the remaining four studies indicated that neither pre-injury occupational level (Cattalani et al., 2002; Devitt et al., 2006; Wagner et al., 2002) nor occupational stability (Doctor et al., 2005) was a predictor of post-injury return to work or productive activity.

A survivor's age at the time of injury was another variable that 14 of the 20 research groups examined. In most cases, age at the time of injury was not a predictor variable (i.e., Boake et al., 2005; Cattalani et al., 2002; Doctor et al., 2005; Gollaher et al., 1998; Greenspan, Wrigley, Kresnow, Branche-Dorsey, & Fine, 1996; Leahy & Lam, 1998; O'Neil et al., 1998; Sherer et al., 2002; Simpson, & Schmitter-Edgecombe, 2002;

Table 2-2

*Pre-injury Demographic Variables*

	Previous occupa- tion	Age when injured	Gender/ sex	Marital status	Education	Race/ ethni- city	Social/ behavior problems	Co- occurring disabilities
Arango-Lasprilla, Ketchum, Williams, Kreutzer, Marquez de la Plata, O'Neil- Pirozzi, Wehman, 2008						+		
Asikainen, Kaste, & Sarna, 1996		+			+			
Boake, McCauley, Pedroza, Levin, Brown, & Brundage, 2005	+	-	-		+	*		
Cattelani, Tanzi, Lombardi, & Mazzuchi, 2002	-	-	-		-			
Devitt, Colantonio, Dawson, Teare, Ratcliff, & Chase, 2006	-	*	+	*	*		+	
Doctor, Castro, Temkin, Fraser, Machamer, & Diemen, 2005	-	-	-		+			
Felmingham, Baguley, & Crooks, 2001	+	+						
Fleming, Tooth, Hassell, & Chan, 1999	+		-		-			
Franulic, Carbonell, Pinto, & Sepulveda, 2004			-		+			-

Gary, Arango-Lasparilla, Ketchum, Kreutzer, Copolillo, Novack, & Jha, 2009						+
Gollaher, High, Sherer, Bergloff, Boake, Young, & Ivanhoe, 1998	+	-	-		+	
Greenspan, Wrigley, Kresnow, Branche-Dorsey, & Fine, 1996		-	-		+	+
Keyser-Marcus, Bricout, Wehman, Campbell, Cifu, Englander, High, & Zafonte, 2002	+ at years 1,2,3 & 5	+ at years 1, 2, 3, & 4	-		+ at year 1 only	-
Leahy & Lam, 1998		-	-		-	
MacKenzie, Morris, Jurkovich, Yasui, Cushing, Burgess, deLateur, McAndrew, Swiontowski, 1998	+				+	
McCrimmon, & Oddy, 2006						
O'Neil, Hibbard, Brown, Jaffe, Sliwinski, Vandergoot, & Weiss, 1998		-	-	-	+	
Sherer, Sander, Nick, High, Malec, & Rosenthal, 2002	+	-			+	
Simpson, & Schmitter-Edgecombe, 2002	+	-			+	-
Wagner, Hammond, Sasser,	-	-	-		+	+

Italics denote that the referenced manuscript addressed return to productive activity (RTPA) as opposed to return to work (RTW). RTPA includes those people who have successfully returned to employment, fulltime student status, or homemaker duties.

\* Contributed to the statistical model but was not an independent predictor

■ Author obtained mixed results

Wagner et al., 2002). However, three sets of researchers associated with the reviewed publications (Asikainen, Kaste, & Sarna, 1996; Felmingham et al., 2001; Keyser-Marcus et al., 2002) demonstrated that age at the time of injury was a predictor of RTW.

Asikainen and colleagues (1996) established that those severely injured during childhood or early teen years had worse employment outcomes than those injured as older teens or adults. However, other researchers (i.e., Felmingham et al., 2001; Keyser-Marcus et al., 2002) have reached contradictory conclusions and determined that, generally, survivors who were older at the time of injury were less likely to resume employment post-injury.

In addition, one research group (Walker, Marwitz, Kreutzer, Hart, & Novak, 2006) examined the occupational categories to which survivors returned following injury and found that those in managerial or professional positions were significantly older at the time of injury than their skilled or manual labor counterparts. Finally, Devitt and colleagues (2006) demonstrated that age had a significant bi-variate relationship in their analyses, although they did not find it had a main effect. Similar to age, the variable of gender/sex proved not to be a predictor of RTW or RTPA in the majority of studies that included investigation of this variable (Boake et al., 2005; Cattelani et al., 2002; Doctor et al., 2005; Fleming et al., 1999; Franulic et al., 2004; Gollaher et al., 1998; Greenspan et al., 1996; Keyser-Marcus et al., 2002; Leahy & Lam, 1998; O'Neil et al., 1998; Wagner et al., 2002). Only one group of researchers (i.e., Devitt et al., 2006) found sex to be a significant predictor of RTW. They established that men fared worse when attempting to RTW after brain injury than women. Further, male survivors are more likely to have manual labor jobs than are female survivors of TBI (Walker et al., 2006). The fact that men are more likely than women are to sustain brain injuries, however,

makes this a challenging variable to study (Bounds, Schopp, Johnstone, Unger, & Goldman, 2003). In a recent meta-analysis, Farace and Alves (2000) stated that, despite the notion that women tend to have more favorable brain injury outcomes than men, their results reflected the opposite. However, the researchers cautioned that their conclusion was limited by the fact that very few of the total published reports about TBI outcome described results separately for males and females.

The authors of two studies included pre-injury marital status in their examination of variables predictive of RTW. O'Neil and colleagues (1998) determined that it was not a predictor, while Devitt and colleagues (2006) concluded it was a significant bi-variate factor, although it did not have a significant main effect. However, the type of occupations to which survivors return was key to using pre-injury marital status as a predictor variable (Walker et al., 2006). Specifically, survivors in skilled and manual labor jobs were more likely to be unmarried than those in managerial positions.

Pre-injury education was the predictor variable included in the greatest number of studies selected for review. Sixteen of the 20 studies examining pre-injury predictor variables included it. Furthermore, the majority of them (i.e., Asikainen et al., 1996; Boake et al., 2005; Doctor et al., 2005; Franulic et al., 2004; Gollaher et al., 1998; Greenspan et al., 1996; MacKenzie et al., 1998; O'Neil et al., 1998; Sherer et al., 2002; Simpson, A., & Schmitter-Edgecombe, M., 2002; Wagner et al., 2002) found pre-injury education to be a reliable predictor of RTW or RTPA. More specifically, Simpson and Schmitter-Edgecombe (2002) demonstrated that survivors who were successful in gaining post-injury employment had, on average, more than two additional years of education than survivors unsuccessful in gaining post-injury employment.



Additional work by Keyser-Marcus and colleagues (2002) determined that pre-injury education was only a predictor for those employed one year post-injury but not for those employed at two, three, or five years post-injury. In contrast, Cattelani and colleagues (2002), as well as earlier research groups (i.e., Fleming et al., 1999; Leahy & Lam, 1998), found that education did not predict RTW. Devitt and colleagues (2006) established a bivariate relationship but not a main effect for level of education. Examination of the occupational categories to which survivors returned proved that those with more pre-injury education were more likely to hold managerial or professional jobs than those with less pre-injury education (Walker et al., 2006).

Race/ethnicity was a significant predictor of RTW in 3 of the 6 studies in which researchers included it as a variable (i.e., Arango-Lasprilla et al., 2008; Gary et al., 2009; Greenspan, 1996). In contrast, Keyser-Marcus and colleagues (2002) as well as Wagner and colleagues (2002) determined race/ethnicity was not a predictor of RTW or RTPA, respectively. In addition, an interaction effect may exist between ethnicity and education level (Boake et al., 2005). When specifically investigating job stability (i.e., stable, unstable, or unemployed) as well as employment status (i.e., competitively employed versus not competitively employed) for two groups of brain injury survivors differing on racial heritage, Arrango-Lasprilla and colleagues (2009) adjusted for demographic variables (i.e., pre-injury employment status, age, marital status, education, cause of injury, length of hospitalization, and scores on the Disability Rating Scale (DRS; Rappaport, Hall, Hopkins, Belleza, & Cope, 1982) as well. They established that survivors in the racial minority group were 2 to 3.5 times more likely to be unstably employed or unemployed than survivors in the majority racial group. Similarly and most

recently, Gary and colleagues (2009) examined employment rates at one, two, and five years post-injury to determine whether race differences existed among black and white survivors competitively employed and those not competitively employed. After adjusting for demographic characteristics and injury severity, the investigators found that black survivors' odds for obtaining employment were poorer than those of white survivors, and the disparity was evident at all follow-up times. Specifically, black survivors were 3.15, 2.10, and 2.91 times more likely to be unemployed at five years, two years post-injury, and one year post-injury, respectively, than white survivors. These rates are greater than those that exist for non-injured black and white populations in the U.S. (Gary et al., 2009).

Social or behavior problems were yet another pre-injury variable examined by three groups of researchers. Problems with alcohol, drugs, the law, or psychiatric issues were a significant predictor in RTW and RTPA for survivors of TBI (Devitt et al., 2006; Wagner et al., 2002), making it less likely that those affected would obtain employment. In contrast, personality and family issues prior to injury were not predictive of RTW outcomes (Simpson & Schmitter-Edgecombe, 2002).

Three of the 22 reviewed studies considered pre-injury disabilities as a predictor variable. One set of researchers (i.e., Franulic et al., 2004) found that personality disorders were not predictive of RTW. Likewise, Greenspan and colleagues (1996) concluded that any pre-existing, chronic conditions did not affect RTW. However, psychiatric disabilities made returning to productive activity difficult for survivors of TBI (Wagner et al., 2002). Wagner and colleagues also considered whether a survivor had incurred a previous head injury and found that this factor was not predictive of RTPA.

Two possible predictor variables not included in Table 2-2 are household income and job satisfaction. These variables were excluded from Table 2-2, because only one study each of the one reviewed included them as variables. Specifically, O'Neil and colleagues (1998) included household income as a variable but found it was not predictive of RTW. Likewise, pre-injury job satisfaction was not predictive of RTW post-injury (McCrimmon & Oddy, 2006).

**Injury Severity Variables.** Researchers who have studied the likelihood of injury severity variables predicting RTW have used a variety of injury severity indicators including: (a) admission Glasgow Coma Scale scores (GCS; Teasdale & Jennett, 1974); (b) length of coma (LOC); (c) length of posttraumatic amnesia (PTA); (d) standardized measures; (e) length of stay (LOS) in rehabilitation, acute care, or total hospitalization; (f) CT scan abnormalities; or (g) hospital admission status. Seventeen of the 22 reviewed studies included at least one of the aforementioned injury severity variables (see Table 2-3).

Nine of the 17 studies relied on GCS scores as a measure of injury severity. The authors of five of these studies (i.e., Cifu et al., 1997; Doctor et al., 2005; Felmingham et al., 2001; Fleming et al., 1999; Wagner et al., 2002) concluded, in general, that lower GCS scores upon admission corresponded with poorer vocational or productivity outcomes for survivors. Authors of the remaining four studies (i.e., Cattelani et al., 2002; Franulic et al., 2004; Gollaher et al., 1998; Sherer et al., 2002) determined that GCS scores were not predictive of RTW.

LOC was predictive of RTW in all studies in which the researchers included it as a predictor variable (i.e., Cattelani et al., 2002; Cifu et al., 1997; Devitt et al., 2006;

Simpson, & Schmitter-Edgecombe, 2002). In all cases, the general pattern was that the longer the coma or state of impaired consciousness, the poorer the vocational outcome. However, Devitt and colleagues (2006) concluded that LOC was only significant in their bivariate analyses and that it was not an independent predictor. More specifically, Cattelani and colleagues (2002) examined two groups of TBI survivors—those who had been re-employed and those who had not—across multiple variables and concluded the mean length of coma for the re-employed participants was 28 days, whereas the mean length of coma for the non-re-employed survivors was 108 days. The authors concluded that both the length of coma and length of PTA were the strongest acute predictive factors of who was likely to return to their pre-injury work. Length of PTA was examined by two additional groups of researchers (i.e., Cifu et al., 1997; Fleming et al., 1999), both of whom determined that the longer the survivor remained in PTA, the less likely he/she would be to RTW.

Authors of three of the 17 studies that examined injury severity variables included a standardized measure of severity. All three research groups (i.e., Boake et al., 2005; Greenspan et al., 1996; Wagner et al., 2002) used the Injury Severity Score (ISS; Baker, O'Neill, Haddon, & Long, 1974), but only Boake and colleagues (2005) found it to be predictive of RTW. They found that survivors with more severe injuries had longer absences from work than survivors with less severe injuries. Greenspan and colleagues (1996) examined injury severity using both the ISS and the Abbreviated Injury Scale (AIS; Committee on Injury Scaling, 1985). They determined that only the AIS was predictive of RTW, indicating that those with more severe injuries had less independence,

Table 2-3

*Injury Severity Variables*

	GCS	LOC	Length of PTA	Severity (Standard- ized measure)	Cause of injury	LOS in rehabili- tation	LOS in acute care	LOS	Hospital- ization admis- sion	CT scan abnorm- alities
Boake, McCauley, Pedroza, Levin, Brown, & Brundage, 2005				+	-				+	
Cattelani, Tanzi, Lombardi, & Mazzuchi, 2002	-	+	+							-
Cifu, Keyser-Marcus, Lopez et al., 1997	+	+	+			+	+			
Devitt, Colantonio, Dawson, Teare, Ratcliff, & Chase, 2006		*				*				
Doctor, Castro, Temkin, Fraser, Machamer, & Diemen, 2005	+									+
Felmingham, Baguley, & Crooks, 2001	+			-						
Fleming, Tooth, Hassell, & Chan, 1999	+		+				+			
Franulic, Carbonell, Pinto, & Sepulveda, 2004	-									
Gollaher, High, Sherer, Bergloff,	-									

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Boake, Young, & Ivanhoe, 1998

Greenspan, Wrigley, Kresnow,  
Branche-Dorsey, & Fine, 1996

Keyser-Marcus, Bricout, Wehman, -  
Campbell, Cifu, Englander, High, &  
Zafonte, 2002

Leahy & Lam, 1998

O'Neil, Hibbard, Brown, Jaffe,  
Sliwinski, Vandergoot, & Weiss,  
1998

Sherer, Sander, Nick, High, Malec, -  
& Rosenthal, 2002

Simpson, A., & Schmitter-  
Edgecombe, 2002

*Wagner, Hammond, Sasser,*  
*Wiercisiewski, 2002*

Walker, Marwitz, Kreutzer, Hart, &  
Novak, 2006

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Italics denote that the referenced manuscript addressed return to productive activity (RTPA) as opposed to return to work (RTW). RTPA includes those people who have successfully returned to employment, fulltime student status, or homemaker duties.

■ Author obtained mixed results

\*Contributed to the statistical model but was not an independent predictor

and this negatively influenced their RTW. Another group of researchers (i.e., Wagner et al., 2002) examined several measures of severity and found the Revised Trauma Score (Gilpin & Nelson, 1991) and the Combined Trauma Score, Injury Severity Score (Champion, Sacco, Carnazzo, Copes, & Fouty, 1981) related to RTPA in their uni-variate analyses. These researchers did not find a relationship between AIS or ISS scores and survivors' return to productive activity.

Likewise, three of the 17 research groups examined cause of injury as a predictor variable and obtained mixed results. Greenspan and colleagues (1996), who found a relation between the cause of injury and RTW, categorized the cause of injury into five groups: motor vehicle accidents, falls, assaults, self-inflicted injuries, and other. The researchers concluded that people who sustained intentional injuries (i.e., those with assaults or self-inflicted wounds) experienced more failure to RTW than those with other types of injuries. Similarly, Keyser-Marcus and colleagues (2002) divided their participants into those who sustained injuries through vehicular crashes, acts of violence, falls, and sports-related injuries; these researchers, however, did not find significant differences based on injury etiology in terms of post-injury RTW. A similar conclusion was reached when researchers characterized participants as either having a violent mechanism of injury or a nonviolent mechanism of injury in that a significant finding regarding RTPA did not result (Wagner et al., 2002).

Several groups of researchers examined a survivor's LOS as a predictor variable for RTW or RTPA, although they classified LOS in different ways: Four research groups (i.e., Cifu et al., 1997; Devitt et al., 2006; Keyser-Marcus et al., 2002; Leahy & Lam, 1998) examined LOS in rehabilitation; two (i.e., Cifu et al., 1997; Fleming et al., 1999)

examined LOS in acute care; and one (i.e., Boake et al., 2005) examined hospital admission versus treatment and discharge from an ED. In general, the longer the stay in any medical setting, the less likely a survivor was to RTW. Devitt and colleagues (2006) reached the same conclusion through performance of a bi-variate analysis. In fact, every research group (i.e., Boake et al., 2005; Cifu et al., 1997; Devitt et al., 2006; Fleming et al., 1999; Keyser-Marcus et al., 2002; Walker et al., 2006) that included LOS determined that it was a significant predictor variable.

The final aspect examined in the injury severity variable group was whether medical professionals detected CT scan abnormalities. Three groups of researchers examined this variable and obtained conflicting results. Cattelani and colleagues (2002) established that CT scan abnormalities were not a predictive factor in RTW, whereas two other research groups (i.e., Doctor et al., 2005; Wagner et al., 2002) concluded that employment or productive activity was less likely for those with abnormal CT scan findings.

**Post-injury Demographic Variables.** Of the 22 studies reviewed, 13 included post-injury demographic variables as potential predictors of RTW or RTPA. These variables were: time since injury, current age, marital status, current independent living status, financial support, availability of transportation, drug and alcohol use, current occupation, income, job qualifications, and physical deficits. Table 2-4 lists these variables, their corresponding studies, and general research findings.

Three of the 13 research groups who examined post-injury demographic variables included time since injury as a variable. For this variable researchers obtained contrasting results. Two groups (i.e., Cattelani et al., 2002; Simpson, & Schmitter-Edgecombe, 2002)



Table 2-4

*Post-injury Demographic Variables*

	Time Since Injury	Current Age	Marital Status	Independ- ent Living Status	Financial Support/ Benefits	Availab- ility of Transpor- tation	Drug and Alcohol Use	Occupa- tion	Income	Job Qualifi- cations	Physical Deficits
Cattelani, Tanzi, Lombardi, & Mazzuchi, 2002	+										
Devitt, Colantonio, Dawson, Teare, Ratcliff, & Chase, 2006						+					+
Doctor, Castro, Temkin, Fraser, Machamer, &Diemen, 2005								-			
Felmingham, Baguley, & Crooks, 2001								+			

Fleming,  
Tooth,  
Hassell, &  
Chan, 1999

-

Franulic,  
Carbonell,  
Pinto, &  
Sepulveda,  
2004

+

-

+

Greenspan,  
Wrigley,  
Kresnow,  
Branche-  
Dorsey, &  
Fine, 1996

-

Keyser-  
Marcus,  
Bricout,  
Wehman,  
Campbell,  
Cifu,  
Englander,  
High, &  
Zafonte, 2002

-

Leahy & Lam,  
1998

-

MacKenzie,  
Morris,  
Jurkovich,

+

+

\*

+

+

+

Yasui,  
Cushing,  
Burgess,  
deLateur,  
McAndrew,  
Swiontowski,  
1998



O'Neil,  
Hibbard,  
Brown, Jaffe,  
Sliwinski,  
Vandergoot,  
& Weiss,  
1998

-

Simpson, A.,  
& Schmitter-  
Edgecombe,  
2002

+

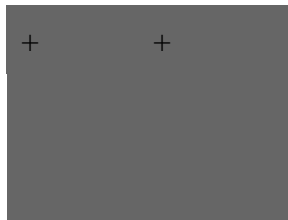


-

*Wagner,  
Hammond,  
Sasser,  
Wiercisiewski,  
2002*

+

+



+



-

Italics denote that the referenced manuscript addressed return to productive activity (RTPA) as opposed to return to work (RTW). RTPA includes those people who have successfully returned to employment, fulltime student status, or homemaker duties.

\* Bivariate relationship but not a predictor in the final regression model

concluded that the length of time since injury was predictive of whether a survivor gained employment. Cattelani and colleagues (2002) found that unemployed survivors were longer post-injury than employed survivors were, whereas Simpson and Schmitter-Edgecombe (2002) found the opposite—that is, their unemployed group of participants had a shorter time since injury than their employed group. O’Neil and colleagues (1998) determined that time since injury was not predictive of RTW.

Four of the 13 research groups examined current age as a predictive variable of RTW and obtained varied results. Two of these research groups (i.e., Franulic et al., 2004; MacKenzie et al., 1998) determined that a survivor’s age at the time of the study was predictive of RTW. Both sets of researchers concluded that the younger a survivor was the better chance he/she had of finding employment. In contrast, Fleming and colleagues (1999) as well as Leahy and Lam (1998) found that a survivor’s age was not predictive of his/her being re-employed following injury.

All three research groups (i.e., Franulic et al., 2004; Greenspan, Wrigley, Kresnow, Branche-Dorsey, & Fine, 1996; Keyser-Marcus et al., 2002) that included post-injury marital status as a variable found that it was not a predictor of RTW. Despite this, Wagner and colleagues (2002) concluded that independent living status was, in fact, a predictor of RTPA and that all persons who successfully returned to productive activity were “mildly dependent or better” (p.110).

Two sets of researchers (i.e., MacKenzie et al., 1998; Wagner et al., 2002) demonstrated that financial support and/or the receipt of benefits affected RTW and RTPA. Mackenzie and colleagues (1998) established that the presence of benefits positively affected RTW; however, the receipt of compensation and involvement in the

legal system negatively affected RTW rates. Likewise, a payer other than Medicaid increased the likelihood that one would RTPA (Wagner et al., 2002).

Only one group of researchers who authored a study included in the review examined the availability of transportation as a predictor variable. Devitt and colleagues (2006) found a strong bi-variate relation between decreased availability of transportation and poor RTW outcome. The researchers also found this variable to be a significant predictor in their final regression model.

Two research groups that included post-injury demographic variables considered survivors' drug and alcohol use. Mackenzie and colleagues (1998) determined a strong correlation existed between the absence of alcoholism and RTW. However, this variable was not significant in their final regression model. The researchers stated that alcoholism correlated strongly with other variables (i.e., poverty status, education, and occupation) in the model. In addition, Wagner and colleagues (2002) found no indication that drug and alcohol use corresponded to RTPA.

Three research groups examined post-injury occupation as a predictor of later RTW. A survivor's employment status at one month post-injury was not predictive of employment status at one year post-injury (Doctor et al., 2005). However, employment status at 6 months post-discharge was predictive of employment status at two years post-discharge (Felmingham et al., 2001). Additionally, MacKenzie and colleagues (1998) found that those who returned to work post-injury, versus those who did not, were more likely to hold a white collar position that was stable, flexible, and had low physical demands than a white collar job without those specifications or a blue collar position.

Two sets of researchers (i.e., MacKenzie et al., 1998; Wagner et al., 2002) examined income as a post-injury predictor variable. MacKenzie and colleagues (1998) determined that those with higher household incomes were more likely to RTW; specifically, survivors whose household income was 125% of the federal poverty level or above had higher RTW rates than survivors with household incomes below this level. Wagner and colleagues (2002) concluded the opposite: Income was not predictive of RTPA.

Franulic and colleagues (2004) established a positive relation between job qualifications and RTW. The researchers state that a lack of job qualifications leads to a poor prognosis of RTW.

Finally, three sets of researchers examined the relation between physical deficits and RTW and found contradictory results. Devitt and colleagues (2006) used the Physical Function subscale of the Medical Outcomes Study Short Form-36 (SF-36; Stewart & Ware, 1992) and found that the more affected a person was by physical deficits, the worse his/her RTW prognosis was. MacKenzie and colleagues (1998) also found a significant relation between physical deficits and RTW. Specifically, 25% of survivors with lower extremity impairments did not RTW by one year post-injury. This contrasted with the findings of Simpson and Schmitter-Edgecombe (2002) who examined physical disabilities with a background questionnaire and found no relationship between it and RTW.

**Outcome Variables.** Sixteen of the 22 studies reviewed (see Table 2-5) included at least one of the following variables: cognitive outcomes, functional outcomes, physical outcomes, general mental health, verbal intelligence quotient (VIQ), performance

Table 2-5

*Outcome Variables*

	Cogni- tive out- comes	Func- tional out- comes	Physical out- comes	General Mental Health	VIQ	PIQ	Full scale IQ	Anxiety	Depres- sion	Mem- ory	Beha- vioral Profile
Cattelani, Tanzi, Lombardi, & Mazzuchi, 2002	+	+			+	+					+
Cifu, Keyser-Marcus, Lopez et al., 1997	+	+									+
Devitt, Colantonio, Dawson, Teare, Ratcliff, & Chase, 2006	+		+	-							
Doctor, Castro, Temkin, Fraser, Machamer, & Diemen, 2005	+	+				+	-				
Felmingham, Baguley, & Crooks, 2001	-			+							-
Fleming, Tooth, Hassell, & Chan, 1999	+	+	-								
Franulic, Carbonell, Pinto, & Sepulveda, 2004	+							+	+		
Gollaher, High, Sherer, Bergloff, Boake, Young, & Ivanhoe, 1998		+									

Author(s) and Year	Effect Size	95% CI Lower	95% CI Upper
Greenspan, Wrigley, Kresnow, Branche-Dorsey, & Fine, 1996	+		
Keyser-Marcus, Bricout, Wehman, Campbell, Cifu, Englander, High, & Zafonte, 2000	+		
Leahy & Lam, 1998	+		-
McCrimmon, & Oddy, 2006	-		+
Sherer, Sander, Nick, High, Malec, & Rosenthal, 2002	+		
Simpson, A., & Schmitter-Edgecombe, M. (2002)			-
Wagner, Hammond, Sasser, Wiercisiewski, 2002	+		
Walker, Marwitz, Kreutzer, Hart, & Novack (2006)	+		

Italics denote that the referenced manuscript addressed return to productive activity (RTPA) as opposed to return to work (RTW). RTPA includes those people who have successfully returned to employment, fulltime student status, or homemaker duties.



intelligence quotient (PIQ), full-scale intelligence quotient (IQ), anxiety, depression, memory, and/or behavioral profile. Cognitive outcomes were included as a variable in 11 of the 16 studies. Eight of the 11 research groups (i.e., Cattelani et al., 2002; Cifu et al., 1997; Devitt et al., 2006; Doctor et al., 2005; Fleming et al., 1999; Franulic et al., 2004; Leahy & Lam, 1998; Sherer et al., 2002) found that cognitive outcomes were a predictor of RTW, while 3 (i.e., Felmingham et al., 2001; McCrimmon, & Oddy, 2006; Simpson, & Schmitter-Edgecombe, 2002) concluded that cognitive outcomes did not play a role in predicting whether a survivor would return to work. The researchers who found a significant relation between cognitive status and RTW used several different standardized measures. Generally, these eight research groups concluded that the better the score on cognitive measures, the more likely a survivor was to have positive RTW outcomes.

Functional outcomes were included in nine of the 16 studies. All of these researchers (Cattelani et al., 2002; Cifu et al., 1997; Doctor et al., 2005; Fleming et al., 1999; Gollaher et al., 1998; Greenspan et al., 1996; Keyser-Marcus et al., 2002; Wagner et al., 2002; Walker et al., 2006) concluded that better functional outcome scores were predictive of successful RTW or RTPA. However, Keyser-Marcus and colleagues (2002) found that outcome scores were only a predictor at 3 years post-injury using one measure and only at 5 years post-injury using another; they did not find significance for this variable for participants at 1, 2, or 4 years post-injury.

Throughout the nine different studies, six standardized measures (i.e., Functional Independence Measure (Forer, 1982); Disability Rating Scale (Rappaport, Hall, Hopkins, Belleza, & Cope, 1982); The Barthel Activity of Daily Living index (Mahoney &

Barthel, 1965); the Glasgow Outcome Scale (Jennett & Bond, 1975), and the Community Integration Questionnaire (CIQ; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) served to quantify survivors' functional outcomes and determine the relation between those outcomes and RTW or RTPA predictions.

Two research groups considered physical outcomes as a variable. Devitt and colleagues (2006) found that those with more deficits that are physical had lower RTW rates. In contrast, Fleming and colleagues (1999) found that physical outcomes were not predictive of RTW.

Only two research groups considered general mental health as a predictive variable. Felmingham and colleagues (2001) determined that the more mental health concerns a survivor had, the less likely he/she was to RTW. However, Devitt and colleagues (2006) determined that mental health was not a predictive variable in RTW.

Cattalani and colleagues (2002) were the only researchers to consider VIQ in their investigation of variables predicting RTW. They found that the higher the VIQ scores, the more likely the survivors were to re-gain employment. PIQ, on the other hand, was included in 2 studies (Cattalani et al., 2002; Doctor et al., 2005). Results from both two research groups indicated a positive relation between RTW and PIQ. In contrast to its counterparts, full scale IQ was not a significant variable in either of the studies (i.e., Doctor et al., 2005; Leahy & Lam, 1998) that included it.

Some researchers jointly examined anxiety and depression. Franulic and colleagues (2004) found that high anxiety was a negative predictive factor in re-employment; in contrast, McCrimmon and Oddy (2006) concluded that anxiety was not

predictive of returning to work. Both research groups, however, found that the presence of depression made it less likely that a survivor would RTW.

Two research groups included a survivor's memory score on a standardized measure as a potentially predictive variable of RTW. Leahy and Lam (1998) found that memory was not a predictive factor. Contrarily, McCrimmon and Oddy (2006) concluded that better memory scores were indicative of higher RTW outcomes.

The final predictive variable examined was a survivor's behavioral outcome scores using an examiner checklist or various standardized measures. Four research groups included this aspect in their studies. Two of the research groups determined this factor was predictive of RTW. Specifically, Cattelani and colleagues (2002) demonstrated that persistent behavioral problems were more likely to be present among unemployed survivors; and Cifu and colleagues (1997) concluded that better scores on behavioral measures indicated more positive RTW outcomes. In contrast, neither Felmingham and colleagues (2001) nor Simpson and Schmitter-Edgecombe (2002) found significant relations between behavioral outcomes of survivors and their re-employment.

Evidently, researchers have made many attempts to clarify why survivors of brain injuries have such a difficult time with RTW and RTPA. Researchers have studied some predictors repeatedly, such as pre-injury level of education, gender, and cognitive and functional outcomes. Other predictors—such as LOC, marital status, and post-injury depression—have been included as predictor variables in few studies. Pre-injury education as well as cognitive and functional outcome scores have been included in many studies and appear to be predictive of post-injury employment, while predictor variables

such as gender and marital status appear to have little to no predictive value in judging which survivors will RTW or RTPA and which will not. Many of the remaining predictor variables have mixed findings. Still others have limited results due to the low frequency of times they have been included in empirical studies. Further complicating interpretation of findings concerning these variables is the vast number of standardized tools used for measurement purposes when trying to quantify variables such as injury severity and cognitive outcomes.

Much ambiguity persists about which factors are most salient to survivors' RTW or RTPA. Hence, the purpose of this study was to address this issue by exploring the employment experiences of survivors of severe TBI who have differing patterns of post-injury employment. The research design involved the use of a mixed method approach. The researcher first used quantitative procedures to add to the body of evidence by confirming or disconfirming the data past researchers have obtained. The researcher achieved this by examining occupational distribution data among a group of TBI survivors. The researcher then collected qualitative data both to inform the quantitative data set and to provide a deeper understanding than is possible using traditional methods of the RTW experiences of survivors of severe TBI.

## **CHAPTER 3**

### **Phase 1 Methods**

An explanatory sequential mixed method design served to structure the data collection and analysis procedures used for this research. Data collection occurred in two phases. Phase 1 involved quantitative data collection from two sources, a) a database of survivors of severe TBI (N = 283) and b) a group of close relatives of survivors of severe TBI with post-injury employment experiences (N = 20). The researcher obtained information regarding return to productive activity as well as the number of hours devoted to the productive activity from the database. From the close relatives the researcher obtained demographic, injury, and employment history information about each associated person with TBI. The purpose of Phase 1 was two-fold. First, the researcher sought to examine database information (N = 283) about the number of survivors returning to productive activity along with their employment status (i.e., part time or full time). Second, the researcher gathered detailed information through telephone interviews with close family members (N = 20) of survivors of severe TBI regarding the survivors' work experiences.

### **Participants**

The researcher searched an employment income database of TBI survivors who were former residents at a rehabilitation facility in the Midwestern United States. The database consisted of 283 survivors of severe TBI. Twenty adults who were close relatives of a survivor of severe TBI comprised the second group of Phase 1 participants. The researcher based family member participant selection primarily on characteristics of

survivor relatives rather than on family member characteristics. The only criteria relating specifically to family member participants was that they be familiar with the associated survivor's past and current work experiences and speak English as a primary language.

The researcher used three methods to identify prospective participants. First, Quality Living Incorporated (QLI)—a transitional living and rehabilitation facility that provides short term and long term care to survivors of various types of neurological injury—provided the researcher with a de-identified database of 565 survivors of brain injury. Then, the researcher used advertisements to the Brain Injury Association of Nebraska (BIA-NE)—both in person at the annual conference and through a web site posting—briefly explaining the study and asking for those interested to contact the researcher in person, by phone, or by email. Finally, the researcher contacted members of a local support group for survivors of TBI and members of their families and asked if they would like to participate. Using all three sources of identifying prospective research participants, the researcher selected survivors who met the following criteria:

- (a) had sustained a severe TBI as defined by a period of coma extending 1 week or greater (Asikainen, Kaste, and Sarna, 1996) or PTA lasting a minimum of 1 day (Murdoch & Theodoros, 2001)
- (b) were at least 2 years post-injury;
- (c) had adequate hearing acuity for conversational speech;
- (d) spoke American English as a primary language;
- (e) were between 18 and 75 years of age;
- (f) had no history of neurological problems or diagnosed educational

impairments other than those associated with the TBI;

(g) had been injured after having graduated from high school;

(h) had pre-injury employment experiences;

(i) had worked for any length of time post-injury either in gainful employment or a volunteer position;

(j) used natural speech to participate in conversational interactions; and

(k) resided within 200 miles of the researcher's location.

Survivors from the QLI database were discharged from the facility between May 2004 and November 2008. Of the 283 people, the researcher identified 74 who met the participation criteria. The researcher and personnel at QLI mailed a form letter and consent/assent forms to all 74 individuals, along with a letter and consent form for their family member. After receiving 6 positive responses and 6 negative responses (a 16% response rate) a second mailing was completed. The researcher sent fifty-five packets out, and 2 positive and 11 negative responses were received (a 23% response rate). In total,

Through the announcement at the BIA-NE convention, at which approximately 80 survivors and family members of survivors were present, six people expressed interest in participating in the research. Four of these survivor's family members participated in the study. Through the BIA-NE web site announcement—of which there were approximately 300 members including survivors, family members of survivors, and professionals—ten people contacted the researcher either through phone calls or through email to express interest in the study. After expressing interest, the researcher obtained prospective participants' addresses and sent them form letters explaining the research as well as

consent/assent forms. Five of these 10 individuals served as study participants. Twenty eight local support group members received explanatory letters and consent/assent forms through the mail to solicit research participation. Four replied, and 2 participated in the study. Finally, one participant was educated about the study by a colleague of the researcher. This individual contacted the researcher and participated.

### **Phone Interviews**

After identifying appropriate participants and obtaining signed consent/assent forms, the researcher obtained a phone number at which to call a survivor's family member for an interview. The purpose of the interview was to obtain demographic, injury, and work history information (see Appendix A). The researcher also acquired a post injury employment success score, previously defined in Chapter One, for each survivor. The researcher based this score on data obtained through the collected demographic information via phone interviews. The researcher entered all obtained information into a database for analysis.

### **Data Analysis**

The researcher examined the aforementioned database for information regarding survivors' return to productive activity as well as their employment status. Next, the researcher entered all data collected from the family member participants into a database for computation of distribution and descriptive statistics relating to survivors' (a) demographic information, (b) employment status, (c) employment stability, (d) number of jobs held post-injury, (e) PATCOB employment category, and (f) the employment profile.



**Interview Materials**

The researcher used a demographic form (Appendix B) to collect background information from Phase 1 family member participants about each associated survivor.

**Equipment**

The researcher used Microsoft Excel and StatView software to organize and analyze the quantitative data gathered in Phase 1.

## **CHAPTER 4**

### **Phase 1 Results**

The information in this chapter pertains to the quantitative results. These findings relate to the entire database serving as the basis for initial data collection followed by the results from the 20 targeted cases.

#### **Database findings**

One-hundred fifty six survivors (55%) from the 283 cases in the database returned either to paid or volunteer positions in a work environment. The database included information about whether a survivor returned to fulltime work, part time work, volunteer positions, school, or none of these, as well as the number of hours devoted to these activities. Rehabilitation facility staff gathered this information at the time of an individual's discharge as well as 3, 6, 12, 24, and 36 months following discharge. However, the researcher only reported the findings from the database pertaining to the time of discharge and the 3-month follow-up period, because over half of the participants were unavailable for long-term follow-up (see Table 4-1).

The percent of individuals engaged in full-time employment or enrolled in school remained approximately the same between the time of discharge and the 3-month follow-up (Table 4-2). A notable decrease in the percent of people with part-time employment, volunteer positions, and those not engaged in work or school was evident during this period. As shown in Table 4-3, the percent of people devoting 31-40 hours to work/school activities remained the same between the two periods, but all other categories of hours devoted to work/school activities decreased from discharge to 3-

months post-discharge follow-up.

Table 4-1

*Number of 156 Database Individuals for whom Work Status and Hours Worked or Devoted to School were Available or Unavailable at Each Follow-up Time*

Follow-up time	Work status		Hours worked or devoted to school	
	Available	Unavailable	Available	Unavailable
At discharge	136	20	110	46
3 months	70	86	58	98
6 months	57	99	33	121
12 months	68	88	40	116
24 months	35	121	22	134
36 months	27	129	20	136

Table 4-2

*Percent of 156 Database Individuals Engaging in Work or School at Discharge and at 3 Months Post-discharge*

	At discharge	3months post-discharge
Full-time employment	11.54%	12.82%
Part-time employment	19.87%	7.05%
Volunteer position	20.51%	12.18%
Enrolled in School	1.92%	1.92%
None of the above	33.33%	10.90%
Unavailable	12.82%	55.13%

Table 4-3

*Percent of 156 Database Individuals Devoting Specified Numbers of Hours to Work or School at Discharge and at 3 Months Post-discharge*

	At discharge	3 months post-discharge
31-40 hours	11.54%	12.82%
1-30 hours	25.64%	13.46%
0 hours	33.33%	10.90%
Unavailable	29.49%	62.82%

### **Targeted Cases**

The researcher queried 21 family members associated with 20 individual survivors of TBI via telephone interviews. The researcher chose the 20 cases based on the survivor and associated family member's availability to participate. All TBI survivors met the required criteria listed in Chapter 3. To summarize, they were at least two years post-injury, had worked in either a paid or volunteer position since injury, had worked prior to injury, and were 18 years of age or older at the time of injury. All but one of the 20 survivors chose 1 close family member for the researcher to interview. In one case, a survivor suggested that the researcher interview his mother and his sister, due to his mother's memory problems.

The family members interviewed included 10 mothers, 3 fathers, 4 sisters, 3 wives, and 1 aunt. All collected data from phone interviews pertained to the survivor of TBI rather than the family member interviewed. The researcher chose to solicit the information from family members as opposed to the survivors themselves because of the

frequency with which survivors experience substantial memory impairments that negatively affect their recall and reporting of injury and work-related experiences. All telephone interviews took between 10 and 18 minutes to complete.

Data were collected on 13 male (65%) and 7 female (35%) survivors of TBI. Survivors' mean age at the time of data collection was 40.6 years ( $SD = 13.41$ ), with a range of 24 to 72 years. Mean length of time since injury was approximately 8 years, 9 months (i.e., 107.2 months;  $SD = 96.91$ ), ranging from 2 years, 3 months to 28 years.

All survivors had held either a paid position or a volunteer job after injury. At the time of data collection, almost two-thirds ( $n = 13/20$ ; 65%) of the survivors were in paid positions (Figure 4-1). Of those not in paid positions, most participated in volunteer activities. One survivor held both a paid position and a volunteer position. Only one survivor had neither a paid nor a volunteer position at the time of data collection.

**Level of Education.** The researcher classified level of education into five categories: (a) *did not finish high school*, (b) *high school diploma*, (c) *some college or trade school*, (d) *bachelor's degree*, or (e) *graduate degree*. As shown in Table 4-4, the majority of participants had attended some college or a trade school prior to injury. Those either with more or less education than this were relatively equally distributed among the other four categories. Four of the 20 survivors completed further schooling after their injuries. One person shifted from the category of not finishing high school to the category of having some college or trade school experience; another survivor shifted from having completed some college or trade school to having completed a bachelor's degree; and two individuals went from possessing a bachelor's degree to obtaining a graduate degree.

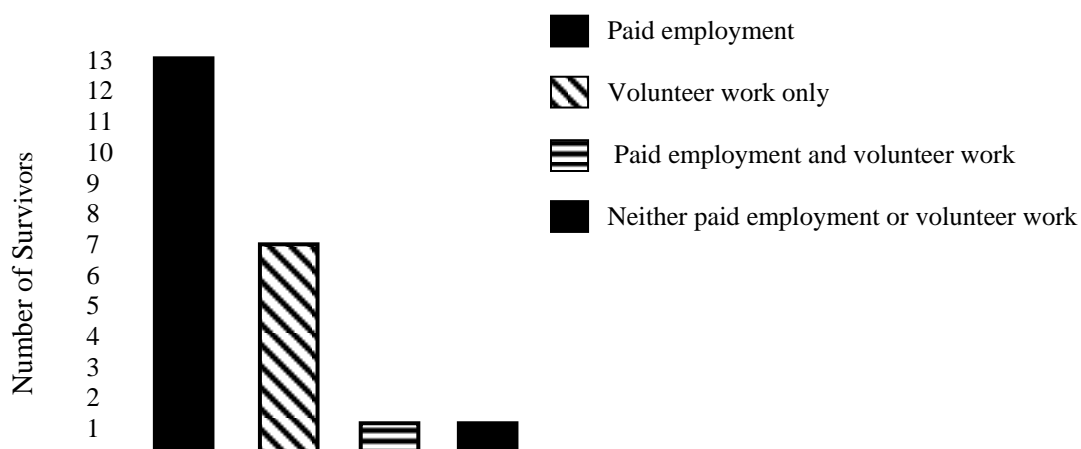


Figure 4-1. Employment status of survivors

Table 4-4

*Number and Percent of Survivors Represented in each Educational Category*

Level of education	Pre-injury	Post-injury
<i>Did not finish high school</i>	2 (10%)	2 (10%)
<i>High school diploma</i>	3 (15%)	2 (10%)
<i>Some college or trade school</i>	9 (45%)	9 (45%)
<i>Bachelor's degree</i>	4 (20%)	3 (15%)
<i>Graduate degree</i>	2 (10%)	4 (20%)

Thus, a slight upward shift in the level of education occurred between pre- and post-injury within the participant group.

**Pre-injury and Post-injury Employment.** All survivors had to have worked since injury—either in a paid position or as a volunteer—to qualify for participation in the study. Likewise, they had to have held a paid position before their injury. None of the participating survivors engaged in volunteer work prior to injury.

***Pre- and post-injury paid positions.*** Figure 4-2 shows a summary of the pre- and post-injury and work classification data as well as the number of survivors working full-time and part-time within each classification category (i.e., *other white collar/blue collar* (OB), *technical/clerical* (TC), *professional/administrative* (PA)). Pre-injury, the majority of people worked in jobs classified as, OB and most worked full-time hours. Post-injury, the majority of survivors again held OB positions. A decrease in the number of people working in the PA realm appeared compared to participant's pre-injury employment status. Most notably, an increase occurred in the number of people working part-time hours after injury as opposed to before injury. Specifically, of the 13 survivors engaged in paid employment post-injury, 6 (46%) worked part-time hours and 7 (54%) worked full time hours (i.e., 31 hours or more). This contrasted with the pre-injury data in which 18 of the 20 (90%) survivors worked fulltime paid positions and only 2 (10%) worked in part-time positions. Less than half (45%) of the 20 TBI survivors reportedly had completed specific post-injury job training or vocational rehabilitation.

Eight survivors (40%) reportedly attempted to return to the same job they had held before injury. Six (75%) of these individuals still held the position at the time of data collection (Figure 4-3). Half of these were in OB positions; one survivor in the PA category returned to work with support; and one in the *technical or clerical* (TC) field returned to work with a decreased number of hours. The remaining two survivors who returned to their pre-injury jobs were no longer working in those positions at the time of data collection because their employers fired them.

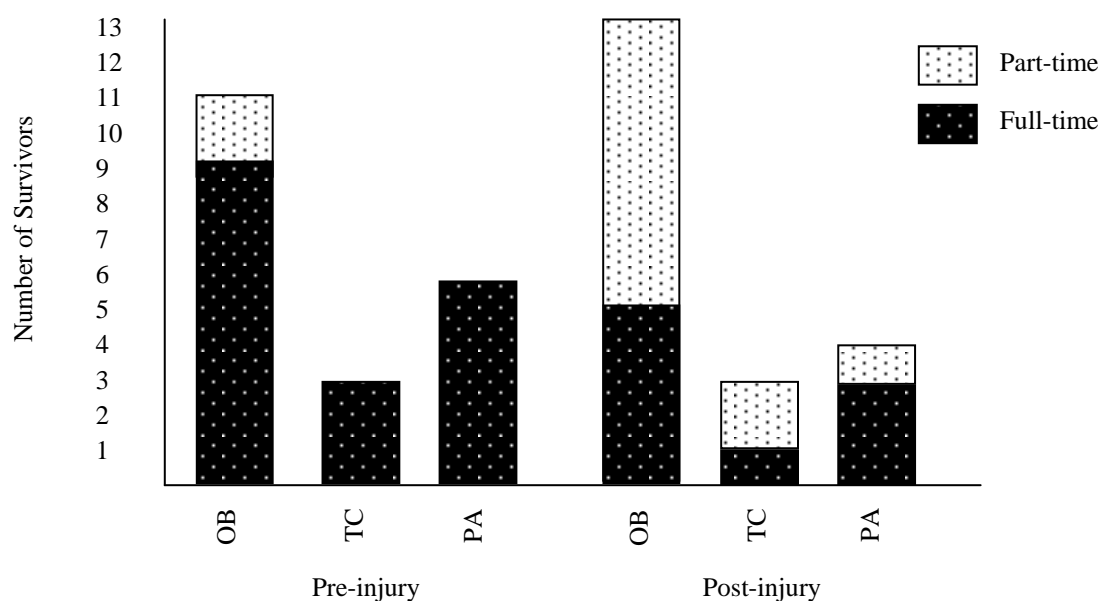


Figure 4-2. Number of survivors working part-time and full-time

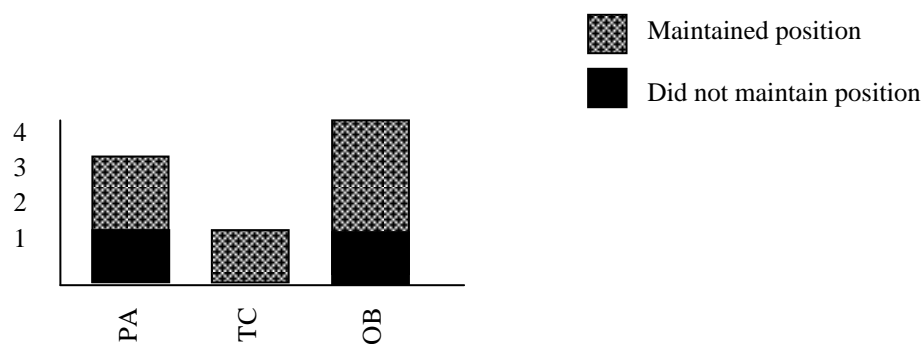


Figure 4-3. Number of survivors (n = 8) in each of the three employment categories who returned to pre-injury positions.

**Post-injury volunteer work.** Six of the unemployed survivors and 1 of the survivors who held a paid position participated in volunteer activities. Of these 7, the average number of volunteer position held post-injury was 2.14 (range = 1 - 5; SD = 1.46). All volunteer positions fell within the OB work category. All survivors who had volunteer positions devoted 20 hours per week or less to their position, except for one



survivor who, between four volunteer jobs, worked 30-40 hours each week.

**Profiles.** Profiles consisted of four letters denoting employment stability (S or U), number of jobs (M or F), and job category post-injury (OB, TC, or PA). As shown in Figure 4-4, the profile with the largest number of survivors was SFOB. Thirteen of the 20 survivors (65%) held positions in the *other white collar/blue collar* job category. Even without inclusion of individuals performing volunteer work only, over half ( $n = 10/17$ ; 59%) of the survivors held *other white collar/blue collar* positions. Twenty-three percent ( $n = 4/17$ ) held *professional/ administrative* jobs, and 18% ( $n = 3/17$ ) held *technical/clerical* positions. Most survivors ( $n = 10/17$ ; 59%) had held few positions since injury and were stable ( $n = 11/17$ ; 65%) in their employment, having one to two post-injury jobs and holding at least one position for more than one year.

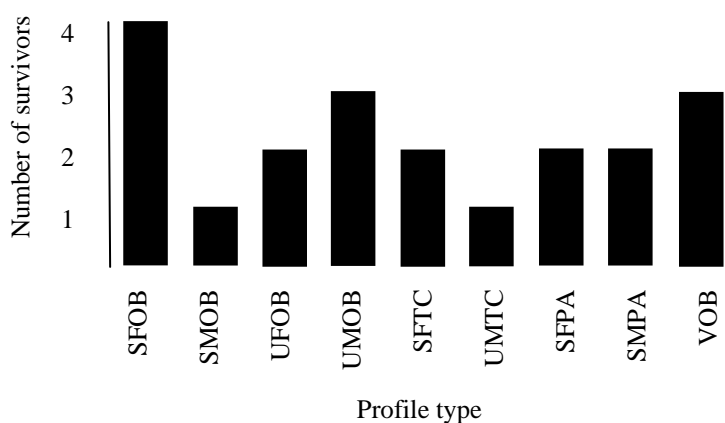
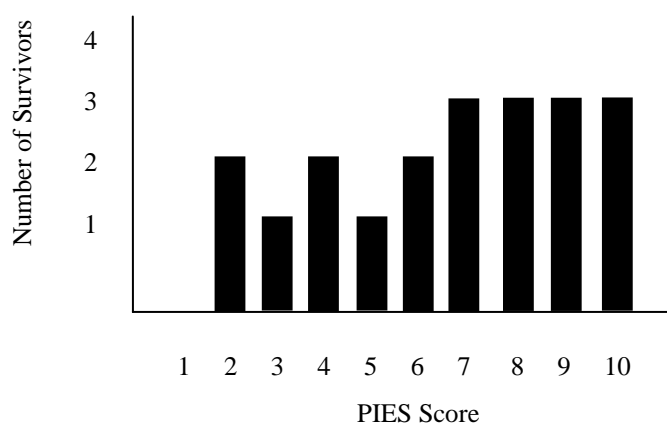


Figure 4-4. Number of survivors in each profile

**Post-injury employment success score.** The researcher also assigned each survivor a post-injury employment success score (PIES). The PIES scores represented survivors' current level of employment achievement regarding job stability, number of

jobs, current employment status (i.e., the success of returning to the same job held prior to injury), and current weekly hours worked. All of the aforementioned constructs were rated either on a 1-2, 1-3, or 0-3 scale (see Chapter 1 for detailed information); hence, PIES scores could range from 1-10, but, because a criterion for study inclusion was obtainment of a post-injury paid or volunteer position, PIES scores for study participants ranged from 2-10. As shown in Figure 4-5, a larger number of participants' PIES scores ranged from 7 to 10 points than from 2 to 6 points. The average PIES score was 6.7 points ( $SD = 2.62$ ).



*Figure 4-5.* Number of survivor participants with various PIES scores.

## CHAPTER 5

### Phase 2 Methods and Mixed Method Analysis

Phase 2 began with participant selection from a subset of Phase 1 individuals, followed by the collection of qualitative data from them as well as the TBI survivors associated with them. Whenever possible, the researcher interviewed a current or past job supervisor associated with each survivor. Collected qualitative data consisted of in-depth inquiries regarding the employment experiences of the TBI survivor participants. The final portion of this chapter explains the mixed method data analysis procedures.

#### Phase 2 Participants

Twelve people participated in Phase 2 of the research. This phase consisted of qualitative data collection through interviewing three groups of participants: (a) 5 survivors of TBI associated with a subset of family member participants from Phase 1, (b) the subset of the Phase 1 family members who were associated with the survivor participants, and (c) current or past job supervisors of the TBI survivor participants.

**Survivor participants.** Five survivor participants associated with a subset of the Phase 1 family member participants constituted the group of survivor participants. The researcher based participant selection on the maximal variation displayed in the survivors' employment patterns and demographic features. The principle of maximal diversity allowed for representation of the complexity of post-injury work experiences and the unique circumstances of individual TBI survivors. The researcher selected 5 survivors who fit as many different employment profiles as possible and were available to participate.

The 5 qualitative participants with TBI selected for Phase 2 were Bob, Carl, Sara, Shelly, and Wade. They varied among one another in terms of length of time post-injury, level of education, ability to return to their pre-injury employment, length of maintenance of their pre-injury job, current employment status, employment profile, and post-injury employment success score (PIES) (see Table 5-1). The following paragraphs provide explanations of the range of diversity among participants with regard to these factors.

Table 5-1

*Information used for Participant Selection for Phase 2*

Survivor:	Bob	Carl	Sara	Shelly	Wade
Time post-injury:	2 years; 10 months	8 years; 10 months	2 years; 3 months	18 years; 7 months	7 years; 8 months
Level of education:	Did not graduate high school	Graduate degree	Graduate degree	Bachelor's degree/ Graduate degree	Some College
Returned to pre-injury job:	Yes	Yes	Yes	Yes	No
Length of time of pre-/post-injury job maintenance	4 months	8 years (on-going)	2 years (on-going)	4 months	Not applicable
Employment status:	None	Full-time	Full-time	Full-time	Volunteer
Profile:	UFOB	SFPA	SFPA	SMPA	VOB
PIES score:	3	9	10	8	1

Following this, separate sections provide additional background details about each survivor participant.

Regarding time post-injury, the five participants ranged from two years, 3 months to 18 years, seven months. For level of education, they fell into four different pre-injury categories and three different post-injury categories. The different number of categories was because Shelly had a bachelor's degree pre-injury but earned a master's degree after injury. The survivors fell into three groups in terms of returning to their pre-injury employment position: (a) those who returned to their pre-injury job and maintained it, (b) those who returned to their pre-injury job but did not maintain it, and (c) those who did not return to their pre-injury position.

Possible employment status categories were full-time paid employment, part-time paid employment, full-time volunteer employment, part-time volunteer employment, and no paid or volunteer employment. Of note, Table 5-1 indicates that three survivors (i.e., Carl, Sara, and Shelly) had full-time job positions; however, only two of these individuals actually worked full-time hours; Carl shared his full-time position with his wife.

The 5 survivors fell into 4 of the 12 different employment profiles described in Chapter 1. Bob was the only survivor with unstable employment (i.e., holding the current or most recent job position for 6 months or less). Because he had held 2 jobs post-injury, all of which fell into the *other white collar/blue collar* category, his employment profile was UFOB. Carl, Sara, and Shelly demonstrated stable employment patterns. Carl held 2 jobs post-injury that fell into the *professional/administrative* job category and, therefore, his profile was SFPA. Likewise, Sara held one job post-injury in the

*professional/administrative* category and had the SFPA employment profile. Shelly held more than twelve jobs post-injury, most of which were in the *professional/administrative* occupational realm; thus, Shelly's profile was SMPA. Wade held only volunteer positions and, hence, did not receive a profile assignment regarding employment stability or number of jobs. All of Wade's post-injury work was in the *other white collar/blue collar* category; therefore, Wade's profile was VOB. Notably, all of the targeted cases who worked in volunteer positions worked in the *other white collar/blue collar* job group. Unfortunately, none of the participants among the 20 targeted cases who worked in *technical/clerical* positions were candidates for the qualitative portion of the study due to unavailability or a lack of family member participation.

The post-injury employment success (PIES) scores provided a means of indicating how successful a survivor had been in terms of employment since injury. PIES scores could range from 0 -10. However, all survivors included in this study scored a 1 or above. The 5 Phase 2 participants' PIES scores were somewhat dichotomized, with three survivors (i.e., Carl, Sara, and Shelly) obtaining the top 3 scores and the other two survivors (i.e., Bob and Wade) obtaining the bottom 2 scores; none of the qualitative Phase 2 participants had PIES scores between 4 and 7.

**“Bob.”** Bob was a 55-year-old husband, father, and grandfather who suffered a fall and subsequent brain injury. His injury occurred 2 years, 10 months before the time of data collection. Bob had not finished high school and had held two full-time jobs in the construction industry prior to his injury. He had worked at one of the jobs for 13 years and the other for 25 years; he was working at the latter position at the time of injury.

Bob did not lose consciousness at the time of his injury; however, he experienced posttraumatic amnesia (PTA) for about 40 days. He did not receive post-injury job training, but his therapists incorporated job tasks into his rehabilitation. Bob returned to work at the same place he had been working before his injury. He worked there part time for four months before his termination. Since leaving his job, he had interviewed for work in his field, but had not been hired. He continued to do remodeling projects around his home but stated, “They take longer than they used to take.” He also helped his wife, Colleen, with her in-home business.

Colleen described her husband’s activity level both before and after his injury by explaining: “He was an all day guy. I’m talking 6 o’clock in the morning to 9 o’clock at night. Now we’ll have maybe 2 or 3 days of good activity, and then it’s just weeks of down in the ... dumps or he’s just really tired.”

**“Carl.”** Carl and Beth’s life changed dramatically in June 2001 after Carl was in a three-wheeler accident and sustained a life threatening brain injury at the age of 63 years. He was in a state of impaired consciousness for 5 weeks. The researcher interviewed Carl 10 years after his injury, when he was 72 years of age.

Carl had a Master’s degree in education and had taught high school and junior high school English for about thirteen years before he quit and became a full-time insurance agent. Carl started working in crop insurance in 1967, during the summers, while still teaching during the academic year. In 1970, the couple moved to an acreage property and added small-scale farming to Carl’s employment responsibilities. At the time of his injury, between his farming and insurance jobs, Carl was working more than

full time according to his report and that of his wife. After his injury, he returned to the same insurance position but with assistance from his wife. He also returned to farming. At the time of the interview, he worked part-time in the insurance business but had given up most of his farming duties, renting out the majority of their land to neighbors.

**“Sara.”** Sara, a forty-year-old wife and mother of four, worked as a product manager for a software development company. She had a master’s degree in health care administration. She was working part time when she and her three-year-old twins survived a single car accident in February of 2008. Sara lost consciousness for less than 24 hours but suffered a brain hemorrhage and experienced PTA for approximately 8 weeks. Thus, doctors classified her brain injury as severe.

Ninety days after the accident, Sara started driving again. She returned to work at that time in the same position she had held prior to injury but for fewer hours. By five months post-injury, Sara was working the same number of hours—about 25 per week—she had prior to her injury. At the time of data collection, 2 years and 3 months post-injury, Sara was still in the same job position, although for the previous 8 months she had been working full time hours rather than part time. She had been at the job for a total of 13 years.

**“Shelly”.** Shelly, a 42-year-old marathon runner, suffered an assaulted at 23 years of age—18 years and 7 months prior to her interview. She had been working as a graphic designer at the time of the incident and held a bachelor’s degree. The assault was by a man unknown to her and left her unconscious for a few days. Neither she nor her mother could recall for how long she was unconscious, but doctors diagnosed her with a



severe TBI, and she experienced PTA for more than a month. She had a basilar skull fracture as well as a separated shoulder. Her secondary medical problems following the attack were numerous.

Shelly received post-injury job training and, three months after her injury, returned to the job position she had previously held. For about one month, she worked part time, and then she resumed her full time position. About 4 months after returning to work, her employer fired her. Since that time, Shelly had returned to school, earned a Master's degree, and held approximately 12 different jobs. At the time of data collection, she was enjoying a grant coordinator position for which she worked with other brain injury survivors as well as students learning to work with survivors. Shelly had been at that position for approximately 3 years. She showed passion when discussing her current job and goals for the future stating, "People with disabilities could be doing so much more for this world, and that's my mission: To get ... them back into the community, but not to be self-serving, but to be ... credible members of the community again, because I know they can do so much more if given the chance."

***"Wade."*** Wade was 29 years old when he was involved in a single-car accident and sustained a severe TBI. He remained in the hospital for two weeks to treat his medical complications and then spent 4½ months in a rehabilitation hospital. According to his father, Wade's coma lasted 82 days. After discharge from the rehabilitation hospital, he spent 1½ years at a transitional living facility to receive additional rehabilitation services. He then moved to an assisted living apartment within the same

facility and was living there at the time of the interview. The interview occurred when Wade was 7 years, 8 months post-injury.

Wade was working as an assistant engineer for an architecture firm at the time of his injury. He had attended college but had not earned a degree. He had held four jobs prior to injury, including working as a heavy equipment operator and performing diesel mechanic work. He had not returned to paid employment following injury but held two volunteer positions at the time of the interview.

**Family members of TBI survivors.** Five of the 20 Phase 1 participants comprised the subgroup who participated in Phase 2 along with one other family member who did not participate in Phase 1 (i.e., the wife of a Phase 1 and Phase 2 participant). The researcher selected Phase 2 family member participants based on characteristics of their associated survivors as described above. Two of the family member participants were wives of a survivor, and 4 were parents of a survivor (i.e., 3 mothers and 1 father).

**Job supervisor participants.** The job supervisor participant group included one person associated with a TBI survivor participant. The researchers asked each participating person with TBI to provide the name of a current or past job supervisor with whom he/she was comfortable having the researcher interview. The willingness of participants with TBI to allow the researcher to interview past or present job supervisors specified the number of job supervisors included as Phase 2 participants. An additional criterion for participation was that the job supervisor knew about the survivor's brain injury prior to the research study.

### **Data Collection**

The researcher designed Phase 2 using a qualitative multiple case study approach within a constructivist paradigm. The constructivist paradigm encourages exploration of aspects of interest by taking into account the individuality of each participant. Thus, although all participants had some experiences in common, the researcher wished to accentuate the uniqueness of each participant. Consistent with all qualitative research, components of this study were emergent and context-dependent (Guba & Lincoln, 1988; Creswell, 2007). The researcher digitally recorded all semi-structured interviews, which included predetermined and follow-up questions as deemed appropriate. The researcher additionally conducted observations and gathered artifacts, and she made addenda to the verbatim transcripts using field notes, when applicable.

### **Data Analysis**

The researcher completed the qualitative data analysis. To conduct analysis of the qualitative data, the researcher engaged in immersion in the data corpus, identified significant statements, determined core themes and issues, conducted in-depth searches for confirming and disconfirming evidence, and integrated concepts into appropriate categories. Triangulation served to verify themes by examining the different types of data collected. One research assistant, along with the researcher, participated in hand-coding the data by classifying statements within the transcripts into the chosen themes. The team of two completed the process of coding with an 88% inter-rater reliability rate (i.e., the number of disagreements divided by the number of agreements plus disagreements times 100) on approximately 20% of the transcripts. The researcher and research assistant

discussed and resolved all coding and classification disagreements. The primary researcher also conducted a cross-case analysis, searching for common themes and disparities between participants. Debriefing and member checking by individuals participating in the interviews served to confirm the data validity (Creswell, 2007).

### **Mixed Method Analysis**

The mixed method analysis served to join Phase 1 and Phase 2 databases. The researcher achieved this by using quantitative procedures to identify pertinent variables while simultaneously using qualitative data to add depth and richness to the picture (Hogdkin, 2008) and accentuate individual differences of survivors. A quantitative approach was necessary to obtain a PIES score to quantify each survivor's present or recent employment characteristics. The researcher also needed quantitative data to obtain distribution data regarding survivors' a) employment status, b) employment stability, c) number of post-injury jobs held, and d) job categories. These factors affected decisions regarding participant selection for Phase 2.

The researcher searched for confirming and disconfirming evidence between the two data sets regarding the PIES score and the corresponding interview data. Another purpose for comparing the data corpuses was to explore whether and how the qualitative data obtained in Phase 2 informed and elucidated the descriptive results from Phase 1. Finally, through the analysis of qualitative data, the researcher also attempted to determine potential explanations about the employment patterns of survivors and the common employment categories sought by survivors.

### **Materials**

**Interview Materials.** The researcher used one of three interview protocol forms for Phase 2 data collection. The separate, but parallel, interview protocols appearing in Appendices B, C, and D were used with the TBI survivor, Phase 2 family member, and job supervisor participants, respectively.

**Equipment.** The researcher used a Marantz digital audio recorder to record all Phase 2 interviews and a PC laptop computer to transcribe the interviews and aid in the analysis of data. The researcher and her assistant hand-coded all themes rather than using qualitative data analysis software.

## Chapter 6

### Phase 2 Qualitative and Mixed Method Results

#### Qualitative Results

This section pertains to the qualitative findings from Phase 2 for the 5 selected cases. The initial section, Case study results, provides information about each of the 5 survivors' individual cases. The next section addresses the Cross-case results. Within the Cross-case results, the researcher discusses *Employment status* as well as several *Cross-case themes* that emerged during the cross-case analysis.

**Case study results.** This section consists of five parts, each devoted to one of the 5 TBI survivor participants. The individual survivor's themes and subthemes appear in detail and the researcher gleaned illustrative examples from the interview transcripts associated with him or her.

**"Bob."** The researcher used salient content from Bob and Colleen's interview transcripts to develop seven themes. These themes were: (a) *"I did not go back to my old job,"* relating to the fact that Bob's job was much different post-injury compared to pre-injury; (b) *Challenges at Work*; (c) *Strategies*; (d) *"I should have connected the dots,"* pertaining to Bob being fired; (e) *"They tried to hire me for 25 years,"* regarding Bob's struggles with attempting to regain employment; (f) *"Now a days,"* explaining current struggles and strategies Bob and his wife employed; and (g) *"Chasing Cars,"* describing the couple's isolation from family, friends and coworkers.

*"I did not go back to my old job."* Bob and his wife talked about two major points regarding the theme of *"I did not go back to my old job."* First, Colleen explained that Bob was eager to get back to work long before he was ready. Second, both Bob and

Colleen talked about the fact that Bob returned to his pre-injury job but with changed responsibilities and a different relationship between them and Bob's employer.

Bob seemed excited about returning to work after his injury. Throughout his hospital stay, Bob had continually asked about returning to work. His wife described that he was determined to work despite the fact that he still struggled with some major issues. For example, she stated, "He didn't recognize anybody...[but] it was constant, 'gotta get to work.' He knew that he had to work [even though]...he couldn't feed himself, he couldn't walk, he couldn't toilet, didn't bathe himself." Even as Bob emerged from PTA, he focused on construction tasks. For example, he talked about the number of ceiling tiles in his room and the materials used for construction of the hospital. His wife explained, "He had all these big plans to go back to work, and it didn't work out for him."

Bob returned to work with the same company for which he worked pre-injury, but his job responsibilities were different. Specifically, he returned at a reduced number of hours, worked in a different office, and was in charge of computerized inventory rather than warehouse management. His coworkers also treated him differently than they had before his injury. His wife stated, "No one would talk to him when he was at work; that bothered him a lot." Bob also stated of his co-workers, "People you thought were with you hand-in-hand, no matter what, it just turns out that's not the case. They avoided me." Colleen's relationship changed with Bob's coworkers as well. She explained this by saying, "During his injury, his boss called me every week to see how he was doing...every week. And when he went back to work, [we] didn't hear a word from him."

They didn't call and say, '[Bob's] having problems with this' or '[Bob's] doing great' or anything. They never spoke to me after that."

*Challenges at work.* Bob and Colleen commented about several challenges Bob experienced at work. These challenges arose because of obstacles put forth by his superiors, a general lack of support, and difficulties stemming from Bob's limited computer literacy.

Bob's therapists at the rehabilitation facility wanted to enter the work place with Bob to help him work on tasks he would be carrying out upon his return. Of this Bob stated, "They [the therapists] contacted the offices there, and they [the employers] would not allow them to go into the office. ...What they told them was insurance raises, ...which I know after the fact now [is] just a way for them to avoid that, 'cause...any salesman or anybody that sells anything to them [the employers] can walk into our warehouses. They just didn't want to be bothered with it, I guess."

Bob eventually returned to work in a computerized inventory position instead of his previous position as a warehouse manager. This happened despite the fact that one of Bob's biggest challenges at work was working on the computer. Although his wife postulated the problems might have related to his vision, Bob claimed they stemmed from difficulty finding the necessary programs on the computer. Referring to the computer programs, Bob stated, "I had to look for them, ...but they weren't where I thought they were. ...They were in a different category. ... I may have been on that category for let's just say two hours, before I realized that." In addition, Bob did not have anyone he felt he could ask for help, nor did he have anyone supervising him. He stated, "Nobody else



would have had a clue that it took that long 'cause they...didn't watch what I did during the day and stuff, so they never would have known."

*Strategies.* Bob explained to the researcher the types of strategies he used to compensate for his memory problems after returning to work. These were strategies he had not needed prior to injury: "I wrote little messages...just little notes to myself which stayed in my office....I didn't care if the cleaning crew saw them....They were on my desk in plain sight, and anyone could've looked at them, but that's okay." He also said that he kept notebooks to help him remember things.

*Connecting the dots.* Both Colleen and Bob reminisced about the fact that Bob's employer fired him soon after he returned to work. They both felt that, in hindsight, they should have known his employer would let him go, and they concurred that Bob was let go from his job under unfair circumstances. Prior to his injury, Bob routinely borrowed materials from the company and brought them to his home. This was evidently commonplace not only for Bob but for other employees as well. However, when firing him, his employer stated the reason was that he had borrowed materials, which was against company policy, and cited him as untrustworthy. Of this Bob stated, "Now-a-days I connect the dots, but going back 2 years...I would have never, never thought they would've done that to me, but they did. ... I would've connected the dots if it wasn't for what I had wrong with me." Regarding the fact that his employer avoided him at work, Colleen stated: "Now, in hindsight, they weren't gonna keep him. Why keep that relationship going, ... if they're not gonna keep him?"

*“They tried to hire me for 25 years.”* Bob and Colleen made comments about the difficulties Bob experienced trying to obtain employment after his termination. Colleen explained that Bob had had many interviews since leaving his job, but that none of the potential employers hired him. Of the competitors of his former company, Bob stated, *“They won’t even hire me....For 25 years they tried to drag me off whatever I was making,...but now, after my injury, they would not hire me. I’ve approached two or three of them, and they tell me because it’s slow they won’t [hire] me. That’s not the case. I know when they’re slow and busy and stuff.”*

*Now a days.* Colleen cited several challenges she believed Bob would experience were he to return to work now. Specifically, she said that (a) his phone skills were inadequate, (b) “he would tire easily” and not be able to sustain a whole day’s work, (c) “he might act out” if things didn’t go his way, and (d) he had trouble organizing tasks and performing them in the correct order. As an example of the challenges she anticipated, Colleen spoke about Bob’s remodeling projects in their home. She stated that they took him much longer to complete than they used to, saying, *“Whatever’s going on is busy, but he’s just not getting it done.”* Bob agreed, stating: *“[A] tile job used to take me...a day to do it; now it takes me two or three days. ...I still get things done. It just takes awhile.”*

Both informants discussed some of the tactics they have implemented to compensate for Bob’s deficits. For example, they post all of Bob’s appointments on a large wall calendar. Likewise, when doing the family grocery shopping, Colleen cuts out pictures of groceries and their prices from ads to remind Bob which items to buy. She

also stated that when Bob first started running errands, she would have to help him problem solve through certain tasks, such as what to do when the fuel light came on in the car.

*“Chasing Cars.”* Colleen spoke about changes in social interactions with others that she and her husband experienced post-injury. On several occasions, Colleen alluded to the increased isolation she and Bob experienced since the injury. For example, she stated: “We don’t really have much of a relationship with our children now, since his brain injury. This used to be the house [for] every weekend dinners, grandkids spending the night, slumber parties....Not since his injury.” When asked what Colleen attributed that to, she explained: “He’s different. He’s not their dad anymore, and that’s just uncomfortable somehow. He just kinda rambles when he talks, and there’s no intellectual conversation anymore...with their dad.” At another time, she stated, “We are very isolated now [and] it’s not with just us. ... We get the same story from everybody that has a family member or loved one with a TBI. ... It’s with their work, their friends, and their family. [Bob’s] brothers and sisters, they don’t talk to him much anymore.” She also explained that Bob’s lack of friendships and work relationships affected him negatively: “If he sees a construction truck go down the road, I call it chasing cars, because he’ll get up and chase it and see where they’re going, ’cause he wants that camaraderie....And there will be guys that he knows, and he will talk to them on the job site.”

*“Carl.”* The researcher reviewed the three interviews from Carl, his wife Beth, and his work supervisor Nancy, as well as her own observations and notes. Seven themes emerged from this review: (a) *“They get really nasty,”* describing the initial challenges

the family and health care providers incurred following Carl's TBI; (b) *"Nobody would have known,"* detailing the pivotal role family support played in Carl's recovery; (c) *Was that before or after the accident?* detailing major changes since the accident and including descriptions of how Carl and Beth's children and friends reacted to Carl's post-injury personality; (d) *Back to work*, explaining the strengths and challenges Carl and his wife experienced after Carl returned to his pre-injury employment; (e) *Strategies*, including descriptions of how Beth and Carl have compensated for Carl's challenges; and (f), *"Just old age,"* and (g) *Ongoing challenges*, both describing the current obstacles Carl still faces.

*"They get really nasty."* Carl and Beth discussed the challenges they initially faced after Carl's injury, citing memory problems and physical and speech inabilities as being the most pertinent. Beth also spoke about Carl's uncooperativeness and the isolation she felt after he returned home.

Carl talked about not remembering family member's names as a major challenge he experienced immediately following the accident. He stated, "At first I had a little trouble getting everyone into place." With regard to physical functioning, Carl also explained that he could not move his left arm or leg, sit up in bed, swallow, or talk. Beth expanded on Carl's initial challenges:

We could not brush his teeth, because he didn't know how to spit, and a baby even knows how to spit, but he knew nothing. He didn't know a color. He could talk a little. ...He was very nervous and...very hyper.

When he first came out [of impaired consciousness], he was paralyzed...on his left side.

Beth continued by explaining that Carl also demonstrated some behavioral challenges, such as being uncooperative with hospital staff: “They took him into [therapy] two or three times a day. Sometimes [Carl] would refuse to go.... I mean, it’s just the typical brain trauma person. They get really nasty....Unfortunately; he was in that [nasty stage] for two weeks.”

Beth described one of her biggest challenges initially as simply bringing Carl home: “I was really scared...very nervous... to have him come home. It was horrible. I really felt like we had been abandoned, because we had no help out here. There was ...nothing as far as any help was concerned.” Eventually Carl was sent to a larger town for outpatient therapy, but Carl and the therapist “just did not hit it off, and he refused to go [back],” according to Beth.

*“Nobody would have known.”* Beth talked about how important family support was when describing Carl’s initial stages of recovery. She described situations in which she and other family supported Carl by helping him clarify his thoughts when confused, by going along with some requests and remarks despite their irrationality, and by taking time off work to care for him.

As Carl advanced through the stages of impaired consciousness, Beth described him as being very confused. “These things...in their brain...are all mixed up, and it all has to be sorted out and put in place,” she said to describe the basic challenge faced by survivors of brain injury in general. She continued, “I mean, the nurses, they didn’t know

what [Carl] was talking about. Nobody would have known.... It was very, very important for a person who knows them very well...like a spouse...to be there, because they know what [the survivor] is talking about.” While hospitalized, Beth had to find ways to relieve Carl’s anxiety and confusion about not being at work. She gave the following example: “He would say things like, ‘I’ve got to plan a meeting, so Sweetie, you go make a phone call’. So I’d walk out of the room and sit there for two minutes and come back in, and he would be okay.” She explained further that to calm him she would also sit down with a tablet and write “random numbers in a column, and that would satisfy him that we were doing something.” Beth described other situations in which she was glad she was with Carl in the hospital. “He got very agitated; because he didn’t have a watch,...I went down to Kmart and got him a watch....He needed to have a handkerchief [too]. This is what is so important about [having] someone there.”

Beth took 9 months off work to be with her husband while he was recovering and after returning home from the rehabilitation hospital. She explained that she did not feel comfortable leaving him alone for quite some time. After going back to work, she only worked two days each week. She reiterated her point in the form of a recommendation for other families of survivors by saying, “If you really want and need a [good] recovery, somebody that they’re really close to needs to be there, so they know what [the survivor is] talking about, because it’s all mixed up”.

*Was that before the accident or after?* Beth talked at length about how Carl’s and her family and social lives changed following the accident. Carl’s personality changes led to a decrease in social exchanges and changes in patterns of family interactions. Beth

explained that they now dichotomize their life experiences as either occurring *before* or *after* the accident: “Our life now is what happened before the accident and what happened after the accident.”

Beth credited the majority of the social changes she and Carl experienced to Carl’s post-injury personality: “His personality has completely changed. [Before the accident,] he would listen. You could reason with him. He would listen to...your side and maybe agree that maybe you were right. He never would yell, pound the table.” Nancy, Carl’s direct supervisor at work, agreed that Carl’s personality had changed since the accident. She stated:

...attitude-wise it’s almost like he’s got a little bit of a chip on his shoulder....In a way it almost seems like a youngster, because [it’s like] ‘I don’t like the way you’re doing things, so I’m just not gonna do it that way,’ rather than an adult [who] might discuss it....He just doesn’t do it....I didn’t run into that prior to his accident.

Beth explained the personality changes in Carl that she finds most difficult:

[Carl] lost all his emotions. Basically the only emotion he ...[has is] anger. ...I expected him to care about me. I expected him to care about how I felt. I expected him to love me, and he has...nothing. ...This to me is the hardest....If he gets an idea in his head...you can’t reason with him....He just becomes angry immediately. There is no talking; there is no discussing; there is no, well, what a husband and wife do...where they talk and they discuss things and pick whatever is best [for] both.... He doesn’t

reason things out....I'm afraid he's going to get hurt again or something's going to happen, because he has no judgment.

Beth explained that Carl's social interactions had decreased since the injury. She voiced her concern that some friends were uncomfortable with Carl because of his anger. As an example she said, "When you're with somebody and they start pounding the table and yelling because they're telling a story about how someone criticized them...it's gonna make you uncomfortable." She went on to explain that she believes some of Carl's anger stems from a bad relationship with his father, which was a topic he never discussed before the accident. She stated, "I think all of this had been pent up all those years, and now it just comes out." Beth continued, "Some of our friends that we've had from before are very tolerant of it. His personality has changed, and they know it has." Beth looked pained when she spoke of their three adult children: "It's really hard for the kids. It's hard for them to understand their dad, but, as I say, our family has had to change. We've all had to." She explained that when their son who lives nearby attempts to help with farming, Carl gets angry with him, "and this is very hard for [our son]." Their other son lives out of state, and they only see him one or two times a year. She described this son as being in denial about some of his father's changes: "He doesn't want to know it. He doesn't want to realize it. He just tiptoes around his dad.... Our daughter just feels...really bad for Dad, but she has sympathy for the rest of us." Beth finished talking about their changed social and family life by laughing while stating, "We've got some friends that are relatives, so they can't get away from us." Throughout this portion of the interview, Beth repeatedly gestured a small box shape with her hands, possibly indicating



that she believes their world has gotten smaller or become more isolated since Carl's injury.

*Back to work.* Discussion of Carl's vocational strengths and challenges dominated the conversational content relating to the *Back to work* theme. Beth expressed initial concerns about Carl's ability to perform farm work independently. Both Beth and Nancy—Carl's employer—then spoke about occupational strengths and challenges. Finally, all three informants discussed the active role Beth now takes in Carl's work and the fact that she did not have that role prior to his injury.

Carl's first post-injury attempts at employment involved performing farm work. Carl resumed some of these activities in the fall following his June injury. Beth expressed considerable concern and fear about allowing him to work independently around the property: "I went out with him all the time, because I was scared to let him go out by himself. He had to basically relearn how to do the farming machinery."

Carl did not resume work at his insurance position for approximately eight months post-injury. Both Carl's wife and work supervisor commented on orientation and communication skills as being occupational strengths Carl retained despite his injury. For example, even though Carl only had to go to his insurance clients' houses every three years, Beth stated, "He knows exactly where to go. I swear he knows exactly where every town is and how to get there." Nancy praised his communication and interaction skills, stating, "[Carl's] a very good communicator...just very easy to visit with." Carl was also aware of some of his strengths and commented, "My long term memory, I thought, came

back fairly soon and reasonably accurately.” He also stated, “I have not noticed any difficulty with reading. I still read quite a bit.”

Beth iterated some of the problems Carl experienced with his current job activities. She commented about how fortunate he was to be self-employed, because he likely would give an unfamiliar employer a negative impression. She elaborated by saying that Carl gets angry and has a tendency to hold a grudge when he feels criticized: “He just never gets over it...and he will yell about it. He will pound the table.” His work supervisor confirmed that the change in Carl’s attitude since the injury was problematic regarding his employment activities.

Another challenge Beth described was Carl’s inability to complete tasks. Regarding farm work, she explained, “He’ll start out doing something. He’ll talk about it..., but he doesn’t do it. [He] just can’t get started.... That’s what happened to the farming....He couldn’t get the corn in....It was always so late....It was awful.” Likewise, Beth stated that he no longer did crop adjusting as part of his insurance job as he had prior to the accident because of his inability to finish projects: “He can’t do the paperwork. Part of it is because he never finishes anything. He never gets it done...just can’t focus long enough.” She added, “He doesn’t do math well....His handwriting was never too good, but it’s a lot worse now, and usually I fill out the apps for the insurance forms...and do the math, but he goes to see the people.” Nancy, his work supervisor, confirmed that Carl had problems performing mathematical computations accurately and that this had only emerged as a problem since the accident.

The type and extent of assistance Beth provided to Carl in completing work activities emerged as the conversation continued. This was a new role Beth assumed only after the accident, and this added responsibility prompted Beth to quit her former catering job. Prior to Carl's injury, Beth explained their independent work experiences: "I was working full time in a restaurant, ... plus I had a catering business, and he was doing his insurance work on his own. He ... basically did his thing, and I did mine." Following the injury, this was no longer the case. When asked specifically about Beth's changed role, Carl said, "[Beth] certainly spends as much time as I do [working] 'cause she does do the filing and that sorta thing." At the time of the interview, Beth considered Carl's job to be hers as well. She said, "This is the job now, this insurance job. ... I don't work anymore." Beth explained how she and Carl split the work tasks by stating, "It doesn't take me nearly as long as it takes him. So he goes out and makes all the calls ... [and] he brings the bookwork [to me]." She estimated that she worked approximately 20 hours a week on insurance tasks associated with Carl's job and that she was "much more involved than before."

*Strategies.* Both Nancy and Beth provided details about the strategies Carl used to ensure his success at work. In large part, this involved Beth's active role in performing certain aspects of Carl's job for him. Carl acknowledged that initially he needed the help of other insurance agents and now utilized his wife's help extensively. Beth also discussed Carl's resistance to using certain strategies—such as external memory aids—that might allow him greater independence.

One of Carl's most prominent post-injury strategies for success at work involved enlisting the aid of his wife. The following statement from his supervisor illuminated this point:

We would have probably had to let him go if [Beth] hadn't stepped in, because the quality of the work just was not there. I think he's a good liaison between the policy holders, [but] she basically does the work part of the job,...and I think he is more of the social part of it.

Nancy clarified by saying, "I don't see the process. ...The finished product is there. How much of that he is doing, I can't say." Nancy acknowledged awareness that Beth rather than Carl "does the calculation of premiums." Nancy also stated, "I didn't visit with her [i.e., Beth] on the phone prior to his accident. Now,...there's [sic] times I would [rather] just ask his wife the question, because typically she will know as much or more than he does. She's... helped him to that extent now."

Carl acknowledged the adjustments and support he received when going back to work by explaining, "It was [sic] some adjustments to make. I had people who helped me that [first] summer...some insurers that helped me....[Beth] helps me with the paperwork with the insurance to this day." Beth concurred: "As far as his insurance...was concerned, I learned a lot in a hurry about what to do and how to do it." Further, Beth claimed, "This has become my career....Before the accident, I did nothing; he did all of it. I knew nothing about house insurance. He did all the filing. I didn't know anything of that crop insurance...Now,...I go to meetings, although I'm not a licensed agent. It has changed so much, and he can't follow the changes." Likewise, Carl explained that one

thing he finds difficult is that “the insurance industry is never stable-it’s always changing.” Carl, however, did not elaborate on the fact that Beth helped him with that realm of his job.

A problem regarding strategy implementation was that Carl reportedly did not attempt to compensate for his poor memory. His wife stated, “No he won’t do that. He doesn’t think he needs to.” She continued to explain that people will call for an insurance claim, and, if he does not understand their name, he will not ask them who they are. Carl reported trying to implement some strategies when probed specifically about writing things down or using a calendar. Carl responded, “I do try to do that,...but I don’t know if that’s entirely attributed to the accident. We both find that we better put appointments on that calendar up there.”

“...*Just old age?*” The researcher noted that Carl often referred to his age when discussing difficulties such as memory deficits, fatigue, and weakness. For example, he explained his current challenges by saying, “If I have [problems] still, I would say...maybe that’s just old age, [but] I have a little trouble remembering someone’s name.....Someone I knew 50 years ago, that’s easy....But the short term, I suppose I can attribute a little of that to old age.” Another example of this sentiment appeared when Carl talked about external factors (e.g., time of day) that affected his work. Specifically, Carl stated, “When I was younger, I could work to the wee hours at night more easily than I can now, and I don’t know if that’s attributable to the accident or just old age.” Beth partially confirmed Carl’s notion that part of his challenges were due to his age when she stated, “He really lost a lot of strength. Part of it is the accident; part of it is old

age.” At another point in the interview, Carl explained that now he would have trouble painting ceilings and “might fall off the side of the ladder,...but physically I think I’m in reasonable good shape for being 70 some years old....I’m not as strong as I probably was at 40, but I probably wouldn’t have been [even] if I hadn’t had the accident.” He said again, “I probably would have lost a little strength just by aging.”

*Ongoing Challenges.* Several ongoing challenges with which Carl still contended emerged during the course of the interviews. In particular, the informants talked about the persistence of Carl’s left neglect, rambling speech, fatigue, and anxiety. The researcher also observed that Carl engaged in tangential speech and appeared to have little insight into persistent challenges relating to his brain injury.

Regarding Carl’s left neglect, his wife reported, “He had to learn to look to the left and still does.” Beth gave examples of several everyday problems she and Carl faced as a result of his visual neglect. For example, she stated that he might see a check for \$2300 and believe that it was for only \$300. She also said that he fails to use turn signals when he is driving and said, “His driving scares me.”

Both Beth and Nancy discussed Carl’s tendency to chat more than he did prior to his injury, and the researcher also noted a tendency for Carl to display tangential speech during her interview with him. Nancy commented on the rambling nature of Carl’s interactions by saying, “He tends to spend more of the conversation reminiscing. ...Instead of calling and [saying], ‘This is what I need to tell you,’ it’s a 20-minute conversation. And it may be about him growing up, it may be about the weather.” Carl’s wife confirmed this tendency and attributed it to the accident by stating, “One of the

things he does [that] he didn't do before is he talks all the time." She also explained how this affected his work: "He does well at going and seeing the people, visiting with the people,...[but] he has a hard time settling down and focusing....He is more likely to ramble on about something entirely different....He can't focus on what he's there for. I think it's a cover-up." She stated her belief that Carl uses friendly conversation to disguise the fact that he forgets why he is at a person's property or what he was saying. Carl's tangential speech appeared several times during interview, such as when the researcher asked about his going to college. Instead of responding to her question, Carl talked about where he grew up and the type of man his father was. On another occasion, the researcher asked about current challenges at work; Carl spoke for an extended period about farm chores, including details about milking cows when he was a schoolboy. The researcher found herself frequently re-directing the conversation, because of the tangential nature of Carl's responses.

The researcher also noted several instances in which Carl demonstrated a lack of insight. When asked about challenges that persisted at work and that Carl attributed to his brain injury, he claimed, "I don't have any major ones I don't think." He then acknowledged that he did not want to cooperate with his physical therapists when hospitalized. When asked if he had noticed any changes in social or emotional aspects of his life, Carl again demonstrated no awareness of any challenges. Instead, he suggested the researcher talk with his wife about those issues and then talked about his intact long-term memory.

Beth commented about the effects of Carl's decreased stamina and increased anxiety on the activities in which he chose to engage. She said, "He is fatigued,...and things really wear him out. He gets very nervous about things that are up-coming. [He] doesn't like to be away from home....This is his comfort zone. He doesn't want to travel. He doesn't wanna leave."

**"Sara."** The researcher interviewed both Sara and her mother, Martha. Sara was married at the time of the accident and at the time of interview. Sara's mother Martha participated in the interview, however, because she was present for more of Sara's recovery and rehabilitation. While Sara was recovering, her husband spent the majority of his time focusing on their four children. Although the interviews were conducted separately—Sara's first and then Martha's—Martha was present during Sara's interview and often interjected to clarify or add details to her daughter's answers. Sara was also present during the majority of Martha's interview but rarely interjected. Throughout Sara's interview, she discussed how difficult living with a brain injury was for her, "because you can't see the problems, because it's [sic] inside."

Examination of the data corpus revealed seven themes: (a) *"Mommy's head hurts,"* explaining the initial challenges Sara experienced secondary to her TBI; (b) *"You have to fight if you want to get better,"* outlining the role family support played in Sara's recovery; (c) *"I just have a head injury; I'm not contagious,"* describing Sara's process and unique challenges associated with going back to work; (d) *Strategies*, detailing post-TBI accommodations and techniques Sara relied on to ensure her success at work; (e) *"I'm gonna go in the closet,"* providing examples of on-going challenges with which



Sara still contended; (f) *Strengths*, describing personal characteristics that Sara and her mother felt were instrumental to her recovery; and (g) *“Suck it up and quit complaining,”* detailing Sara’s current outlook on her employment.

*“Mommy’s head hurts.”* Sara experienced several challenges upon her initial return home following the brain injury. Among these challenges were interacting with her family; fatigue; emotional lability; poor reasoning; the tendency to become over-stimulated; and poor balance, vision, and memory.

Sara found caring for her children difficult after the accident. She attributed this difficulty to her tendency to fatigue easily. Sara had frequent exchanges with her children about lingering symptoms: “The kids would ask, ‘Why are you so tired?’ ‘Well, mommy’s head hurts.’” At the time of the accident, Sara had three year old twins, a five year old, and a seven year old.

Martha described Sara’s changed emotional state following the injury as being characterized primarily by indifference: “She didn’t even seem excited that I was there.” Martha provided further examples of this indifference by explaining, “The kids made Valentine’s to take up to her room....And she’d look at them and it didn’t mean anything [to her]. ...It was just bizarre.” Martha seemed distraught when describing Sara’s apparent apathy toward her children: “[Sara’s husband] would bring the kids up [to the hospital]. She wouldn’t talk to them, she wouldn’t hug them, she wouldn’t read to them. She just looked at them.” Martha explained that other times Sara was “impossible,” such as the time she became inpatient during a doctor’s office visit. Martha felt compelled to explain her daughter’s irreverent behavior to the nurses by saying, “Listen, I can’t do

anything. She's had a traumatic brain injury. She does not understand. We have to get her in [an examination] room," Martha went on to explain that Sara apologized when the doctor came in, because "She knew she had been a bear."

Martha reported that Sara had trouble with reasoning as well as emotional control during the early stage of her recovery. An example of her poor reasoning was evident when Sara repeatedly tried to get out of bed without calling for help first, as was required because of her poor balance. Martha explained that the hospital staff moved Sara to a room near the nurses' station and put an alarm on her, but she continued to get up without assistance. The hospital staff then put a net enclosure around her bed so that she could not get out without help. Martha also spoke of the time her daughter went on an outing to the grocery store as a rehabilitation activity and displayed poor reasoning: "She drove her cart very recklessly. ...And when she would get out of the car, she wouldn't look for another car or anything, just got out and into traffic." Another example occurred when Sara asked her mother to go for a walk with her outside despite the fact that "it was a terrible winter; it was freezing cold outside." To make matters worse, Martha reported that Sara "headed right for the fire escape."

Both Martha and Sara described Sara's tendency to become over-stimulated. Martha said Sara had always loved football games, but, when they tried to go to one the fall after her accident, Sara "just couldn't stand to stay there." "It wasn't the noise in particular. It was just [too] much going on," Martha explained.

Sara described trouble with balance and vision. As an example, she said, "When we were driving around...I would have my eyes closed in the car, because I couldn't

handle seeing things out the windows.... I couldn't focus on things." She explained that these problems persisted once she left the hospital: "We went to church shortly after I got home.... I had a hard time....standing the whole time. So I would sit and focus in. I would pick one object, and I would just stare at it the whole time, because [otherwise] I couldn't function."

Finally, the women discussed Sara's impaired memory. Sara talked about not remembering the accident. The confusion this caused was evident when she said, "I kept wondering why everybody was coming to our house and being nice to me." She also explained her frustration with entering a room for something and then not remembering why she was there. Martha commented that Sara's memory during her initial stages of recovery "was just odd." She reported that Sara could recognize family members who came to visit and pictures of her children, but she would give incorrect information about where she was, the current year, her age, and her address. Martha emphasized the unpredictable nature of Sara's utterances by saying, "I mean she could say anything! Just anything!" Martha also explained that Sara could remember her user name and password for her online banking account without a problem, but, when asked to make brownies by her occupational therapist, she mimicked doing the entire activity without actually doing any of it. Martha's confusion about Sara's areas of preserved and impaired memory was evident when she said, "This child has been making brownies with me since she was 3 years old. She's only been doing online banking for 3 years at most!" When Sara finally emerged from PTA, Martha reported her saying "Mom, you don't know how comforting

it is that I can remember yesterday.” After that, Martha reported that Sara’s memory was much improved.

*“You have to fight if you want to get better.”* Both Sara and Martha described aspects of family support during Sara’s recovery process. Martha spent a great deal of time at the hospital with Sara throughout her recovery. Martha also tried to foster Sara’s recovery by giving her input about her actions, setting goals for her, and insisting that Sara continue with therapy. Finally, Martha spoke of her protective instincts re-surfacing after Sara’s injury.

The family decided that Sara’s husband needed to be with the children. “They needed a parent,” Martha said. Thus, Martha spent a great deal of time with Sara while she was in the hospital and receiving therapy and Sara’s husband stayed home with the children. Martha described her role in Sara’s recovery and explained that she often tried to rationalize with Sara and motivate her. She recalled a conversation between Sara and her just after Sara’s children had come for a visit:

I’d say to her, ‘[Sara], you didn’t hug the kids at all.’

‘I didn’t?’

‘No, you didn’t. You didn’t say anything to them.’

‘I talked to them, Mom.’

‘No, you didn’t talk to them. You can’t go home until you talk to your kids.’

Martha explained further that she had specific goals for her daughter:

My goal for her was that she could be at [her son’s] birthday party which was [the beginning of] April.... So that was my goal, if she could just

stand to go and be there. ...And my second goal for her was that she would plan [her daughter's] party herself at the end of April. She was able to do those things.

Martha described a time when Sara was particularly agitated and her husband called Martha for advice. Martha reported, "She just had a total breakdown...She thought [the nurses] were giving her shots and injections and all kinds of things." Martha and her husband went to the rehabilitation hospital after receiving the phone call from Sara's husband. She told Sara, "I will stay with you every minute. I will not let anybody hurt you. I will not let anybody touch you. I will be here every minute." From that time on, Martha stayed with Sara "night and day." She accompanied Sara to all of her therapy sessions until Sara finally said, "You don't need to do this anymore, Mom."

Sara eventually became uncooperative with performing therapy activities. Sara would try to bargain with her mother to delay engagement in therapy tasks by saying, "tomorrow I'll do all those things." Then, the next day something else would irritate Sara, and "she would get mad or simply walk out of some treatments." Martha talked with Sara about this behavior and told her:

"'You have to fight if you want to get better. You can't just lay [sic] in this bed and feel sorry for yourself. You've got to fight it, and you've got to prove to people that you can go home.' So she said she would fight. ...I made her sign a contract with me.... And I still keep it! [It said,] 'I agree to work hard at my therapies 3 times a week. I want to be able to drive, cook, grocery shop, return to

work, swimming lessons, attend track and baseball, hug my children, and take care of them. I will work hard to once again be [Sara].”

Martha kept the contract so she could show it to Sara if she refused to go to outpatient therapy after returning home, but Martha reported, “Once we got her [home], she willingly went every day.”

When the researcher asked Martha how her role in Sara’s life had changed, her eyes became teary. She said, “Well, I never use to carry a cell phone on me at all times,” as she pointed to a small pouch slung across her torso. Martha then described how she and her husband were more involved with Sara’s children than they used to be. Martha also said, “I have three daughters. I am an over-protective mother. I admit that. ...But at all their weddings, I told all my sons-in-law, ‘I give them to you.’ And I did. After this happened to [Sara], I took her back.”

*“I just have a head injury...I’m not contagious.”* Sara talked about some of the challenges she experienced with going back to work. She recalled what her first day back was like, her fear that coworkers would look at her differently, the changes in some job responsibilities since her injury, and a newfound problem with performing demonstrations.

Returning to work presented unique challenges Sara had not anticipated. Three months after the injury, Sara went back to work for half days, doing her rehabilitation in the morning and working in the afternoon. Sara recalled, “I remember my first day [back]...I checked my email,...and there were 300 emails, and I got a headache after that, and I said, ‘I’m done.’ And that’s all I did....It was too much.” Sara also described one of

her first meetings after going back to work: “I just felt like everybody was staring at me, waiting for me to do something crazy.” She described her emotions at this time by explaining that she wanted to tell people, “I just have a head injury. I’m not contagious!” She described her co-workers’ behavior by saying, “I think people...just kind of stepped back...to give me space.” In contrast, Sara stated that her direct supervisor did not seem to have hesitations about her returning and was excited to have her back at work. Despite this apparent support and confidence, her employer did not let Sara travel for at least a year and sent another employee with her on the first business trip she made after her return. Sara explained that traveling alone was still a problem: “I just really couldn’t travel by myself. They *would* let me travel for awhile. ...Now they won’t,...because I fainted at work. They are afraid to send me out.”

Sara talked about other work duties she performed prior to her injury that she no longer does. For example, Sara explained that her boss let her write one specification report but had not let her attempt another one since then: “I didn’t do it wrong, but I think I just left parts out.” She went on to describe that employees wrote specifications about software to explain features to computer programmers. Specifications require detail and the ability to assume another person’s perspective. Sara also reported struggling with presenting some demonstrations:

If it’s a really hard demo...very detailed...and [someone] asks a specific question, I have a hard time trying to [explain] how we do things in our software. It’s having to relate [the information] in a way that they

understand. Sometimes I end up saying ‘let me get back to you on that.’ I

have to say that a lot, where I didn’t have to say that a lot before.

Martha noted that the only change she noticed regarding Sara and her work was that Sara worked more than she did prior to her injury.

*Strategies.* Sara gave details about the strategies she now uses to complete her job tasks successfully. Among these were note taking, organizational tactics, and the use of headphones.

Sara began writing notes—something she had not done before her accident—as a means of compensating for memory and organization challenges. When asked specifically about strategies adopted after her injury, she said: “I have an outlook planner. I have a calendar planner. I write in my notebook everything that I have done that day, because then I need to log it in time sheets and, if I don’t write it [down],...I’ll probably forget.” She went on to explain that she remembers her daily activities but not the details about them. To further help her organization, Sara got a new phone containing a calendar on which she “can put personal things in one color,...kids’ activities in another color, work things in another color.”

Environmental factors affect Sara at work because she works in an open office with no walls or cubicles. Because she “can hear everything,” she uses headphones to “tune out everything else.” She claimed her use of headphones helped her remain relaxed and made work easier for her, because they blocked out the noise of co-workers and “the chaos” of the office environment. She further explained her challenges with extraneous noise by saying, “When I can hear other people talking, I start worrying and wondering



what they are talking about. Does it affect something that I am doing? Usually it never does....I think I'm more paranoid [now]."

*"I'm gonna go in the closet."* Certain aspects of cognition persisted as challenges despite Sara's implementation of compensatory strategies. In particular, she reported difficulty with "short term memory," auditory comprehension unless she was "focused and really listening and trying to remember," "poor handwriting," and getting "side-tracked" from her work. Sara and Martha also discussed emotional changes (i.e., overstimulation by large crowds, lower frustration tolerance, and mood swings) as well as a loss of spontaneity.

Sara reported substantial emotional and social changes from her pre-injury status:

I don't like crowds. I like smaller groups, just because it's hard for me to start conversations. I'm good if somebody asks me questions and I can participate. I still have trouble thinking of what I want to ask. Stuff doesn't come to me.

Sometimes I'll plan out what I might ask people.

Martha confirmed that Sara became overwhelmed when surrounded by many people.

Even with family, Sara reported sometimes feeling besieged by the amount of noise and activity:

[My husband] has a big family. Six kids in the family and ...15 cousins.

...I don't like family gatherings still. ...Those are hard. ...There's just too much. Everybody is talking, and sometimes I just want to go into a room and close the door. Just sit by myself. I still get that way [at my house].

I'm like, 'you guys are gonna drive me crazy! I'm gonna go in the closet.'

If [the kids] can't find me they say, 'Go look in her closet!' ...I will just go sit down there in the dark for a while until I feel better.

Another area of emotional challenge Sara reported concerned her tendency to experience dramatic mood swings: "Oh mood swings! I use to be a pretty laid back person, but I get bothered by things now. My feelings get hurt more [than] they used to. ...I'm more emotional. ...It doesn't take much for the kids to set me off."

Martha also noticed persistent changes in her daughter since the accident. In particular, Martha talked about Sara's difficulty handling stress involving her children, problems with short term memory, and postural changes when Sara was very tired. Martha revealed that she did not think Sara had fully regained her pre-injury personality, but she was still hopeful this would happen. She explained that "Someone told us that the brain continues to heal for 5 years, ...and that's what we're anticipating is going to happen." Martha added, "One thing I have noticed is that she has lost her spontaneity." Martha then showed the researcher a family photograph in which Sara's head was "thrown back" and she had a "big huge smile." She said she was still "waiting for that [Sara] to come back." Sara agreed that her spontaneity probably was gone, because she had to think about everything more now.

*Strengths.* The informants spoke of Sara's strengths in addition to her challenges. In particular, they noted her (a) intact long term memory and regained reading comprehension and visual processing skills, (b) her, determination and tenacity during recovery, and (c) her newly-gained parenting skills.

Sara attributed her release from rehabilitation to her good long term memory. Sara said: “That’s how I ended up getting out of rehab, because I could show them what I usually do at work. ...I did a demo for them.”

She also claimed her reading comprehension problems and vision problems had resolved.

Sara spoke of her high level of motivation despite obstacles: “I have a strong desire to do things that I used to do...prior to the accident. ...That’s why I’m determined to do this,” she explained of her reason for training for another marathon despite her mother’s concern that she will pass out from a low blood pressure condition—the same condition that the family believes was responsible for causing her car accident.

Martha reported another strength Sara exhibited was her patience level with her children. Martha said: “I also think she’s a better disciplinarian than she was before, because before she...didn’t make them settle down when she should have. ...They now know. ... She’s not best friend. She’s mom, and she needs to be respected.”

Martha said of Sara’s recovery, “She’s just done marvelously well.” When asked about the factors contributing to Sara’s good recovery, Sara said, “Stubborn disposition.” Martha explained that medical professionals: “attributed it to the fact that she was in very good physical condition. And that she has never been a huge user of alcohol and drugs. Her brain was in very good shape....Everything she did at work she used her brain [for].” Sara addressed this question again later in the interview, and said “family support” was key to her good recovery.

*“Suck it up and quit complaining.”* Sara noted some persistent difficulties associated with work, but both she and her mother provided many examples of positive characteristics of both her job position and her employer. When asked about her job satisfaction, Sara acknowledged that she enjoyed her work more before her injury than she did after: “Sometimes I get pretty bored. ...I feel like I’m not utilized as much [as I was].” Still, she recognized certain benefits associated with her work. For example, her position allowed her to leave by 4:30 or 5:00pm to tend to family issues, and her salary was more than adequate. She acknowledged that these benefits outweighed any negative feelings she had about work and summarized her situation by saying, “So sometimes I just have to say [to myself] ‘suck it up and quit complaining!’”

*“Shelly.”* Four themes and two subthemes emerged from the researcher’s multiple reviews of transcripts and observation notes. Themes included: (a) *Challenges*, describing the initial challenges as well as the current ones Shelly had encountered since injury; (b) *“Hated the job but loved the people,”* detailing Shelly’s extensive experience with jobs held both before and since her injury; (c) *Strengths & Strategies*, explaining both the personal qualities that Shelly possessed as well as the tactics she has used to ensure her post-injury success; and (d) *“So Mad,”* conveying the effect the brain injury had on Shelly’s family. The theme of Challenges included two subthemes *“Ripped off”* and *Lack of Awareness*. The repeated emergence of these subthemes confirmed their particular importance.

*Challenges.* Shelly and Gail both discussed the initial challenges Shelly faced. They explained the cognitive, emotional, and social changes she experienced as well as

her current occupational challenges. When asked generally about the challenges she experienced because of her brain injury, Shelly said, “I would say cognitive [problems] were my worst. Physically, I appeared to be doing great. ... I had balance problems initially. ... Cognitively, I’d say mostly the memory, the planning, [and] the organization skills, which I still struggle with, [were problematic].” She also said that she had concentration, attention, and spatial problems initially and now knows that those were attributable to her “sensory memory impairments.” Shelly’s extensive knowledge about TBI and potential associated problems was apparent when she added that her brain injury was “diffuse,” making it difficult to designate “exactly what was injured.”

Shelley identified fatigue impulsivity, mood swings, and a low frustration tolerance as emotional challenges she faced. As an example, she explained that on the way home from outpatient therapy she “would always stop by the half-price store, and ... buy stuff on impulse.” Regarding her impulsive, post-injury spending, Shelly stated, “That took awhile to amend, but I did it on my own.” She attributed her low frustration tolerance and emotional lability to “all of the frustration, all of the trying to deal with the consequences of the brain injury, and not very many people are understanding, so you don’t really have many resources.”

Shelly’s mother, Gail, talked about cognitive and social challenges Shelly faced immediately after injury. She stated that Shelly initially had “no short term memory [and] didn’t remember the beating. She had to learn everything all over again, how to brush her teeth, how to shower, how to spell, how to write. ... I mean it [was] like the day of her birth all over again. She had to learn everything.” Regarding Shelly’s social challenges,

Gail said: “She lost all of her friends from before ... rather quickly. So everybody is [a] new [friend] now.” Likewise, Shelly talked about an early negative experience she had when returning to a community in which she had lived prior to injury: “Some of the people I knew previously, they would hover over me, talk loudly, and [act like] I was an idiot. They would say, ‘Oh my God, she can talk!’”

Gail also described current challenges Shelly faced: “She still cannot stand large crowds of people [and] noises. Extremely bright lights ... [are] upsetting to her. ... I still notice a misuse of a word every now and then in a sentence.” Gail went on to describe that Shelly still experienced physical challenges as well, explaining that the entire lower body was affected and that Shelly can no longer run.

Shelly talked about some of her current occupational challenges with writing, organizing information, and performing abstract reasoning. Shelly said, “As far as writing papers...[and] trying to put concepts together, [it] takes me much longer, but I am able to do it. ...I would definitely say writing skills [are difficult]. ...I think it’s mostly organization and the planning.” When asked about using an outline to structure her writing, Shelly said, “[I] can’t do that now. It’s very difficult. It’s very frustrating. But I used to find that easy. I got an English minor [in college before my injury].” Shelly also explained that one of her grant coordinator duties was to write a budget proposal, a task that she found extremely frustrating: “I don’t know if it’s numbers or what the heck it is.” She went on to question whether her struggles with this task were because of impaired spatial orientation, mathematical skills, or reasoning. She added, “Am I really struggling

with this because of TBI deficits, or is it because of the [grant] system? ... [Regardless], I like to be ... more grounded ... [rather] than having these abstract concepts.”

The researcher noted multiple occasions where Shelly and her mother discussed instances in which they believed Shelly was taken advantage of due to her disability. The subtheme “*Ripped off*” will document examples of these occasions. Shelly said,

When I was at stores, I know I got ripped off. ... You cannot think of the people giving you the correct change back. I was not able to take the time to count or do it on a piece of paper and... prove... that they were wrong. I think that it happens frequently. I know it does, because they can tell something is wrong with you mentally or cognitively, [and] they try to take advantage.

Gail explained her frustration at not being able to protect Shelly: “I was wishing that she would have been 16 or 17 [at the time of the injury], where her Dad and I could have made decisions for her instead of everybody...letting her make her own decisions, because she wasn’t capable. ... People kept ripping her off.” As a specific example, Gail talked about the time she tried to get Shelly on Disability through the Social Security office.

[Shelly] refused and I said, ‘Why not? You need it. You can’t support yourself.’ And she said, ‘People need it more than I do. Let somebody who really needs it get it.’

I thought for a few seconds after this had happened...to protect her ...

[I’d] become her legal guardian. But about 20, 30 seconds after that, I thought ...it would have destroyed her...and our relationship...for me to

even have asked her. ...I still wanted to protect her, but I knew, when she was with it enough to know what I had done, it would not be so good. So I was kind of scared.

Gail never did become Shelly's legal guardian.

Shelly had a unique perspective on her challenges, as documented in the subtheme *Lack of Awareness*. Shelly recognized her own lack of awareness during her recovery, a phenomenon that may not have been possible without her experiences working with other survivors and of having so many years to reflect on her own capabilities and the changes that occurred since her injury. Shelly stated, "I look back now, and I see so many things now that I thought I was doing fine in, but I wasn't." Gail confirmed this sentiment. When she was in the rehabilitation hospital, her mother explained that Shelly did not think she needed to get better: "She didn't think anything was the matter with her." When asked about returning to her graphic design job and how well she completed her duties compared to pre-injury, she stated, "I really can't say, because there again [I had a] lack of awareness. ... I thought I was aware at the time, but I wasn't."

Shelly also explained that she might have had limited awareness of personality changes that resulted from the injury:

I have had coworkers come back now, from my days at the [newspaper], and they say how different I was personality-wise. They told me I was so introverted...before the injury. And after the injury, I was just out there. And that just shocks me, because, to me, I didn't change that much. There again, lack of



awareness. They said I would tell them anything and everything. Which just scares me [now].

*“Hated the job but loved the people.”* Shelly and Gail both spoke about Shelly’s pre-injury and post-injury employment experiences. They noted Shelly’s unhappiness with her pre-injury jobs and then spoke about her many positions since injury. Both informants provided details about the problems Shelly encountered, but they always reiterated that she enjoyed the work.

Two recurring sentiments emerged as Shelly described her job history. The first was her insistence that she often disliked her job but liked the people with whom she worked. The second was the notion of perseverance with a positive attitude, with Shelly often stating that she would simply try her best. Examples of both sentiments emerged when Shelly spoke of her pre-injury work experience:

I was a graphic designer at [a newspaper]. [I] hated the job but loved the people, so that was nice.

... They were a lot of fun to be around, and I got to draw once in awhile which was my [passion]. I didn’t like computer art, because I had no training in it. ... Yet they expected us to...do some of it, ... [so] you do your best.

Gail confirmed Shelly’s dislike of her work prior to injury by saying: “She didn’t like it. It was [just] a landing spot.” Prior to working for the newspaper, Shelly worked for about one year as a magazine illustrator. Of this job she also stated, “Hated the job, loved the

people.” She explained that “they only paid me five and a half bucks an hour and they expected me to be there for free every weekend and every evening.”

Shelly had a new work supervisor when she returned to her job at the newspaper following her injury. Shelly said, “I believe she was hired to get rid of the [employees] ...but at the time I thought it was just against me, because I had just come there with a TBI. ... [The supervisor said] I wasn’t doing a lot of things correctly even though I was. ...I would continuously ask my colleagues, ‘Am I doing things okay? How am I doing? What’s your assessment?’ They said, ‘You are doing things just the way you used to. Don’t worry about it.’”

Shelly decided to return to school after her employer fired her from her graphic artist position at the newspaper. She enrolled in July of 1992 and got an undergraduate degree in psychology. Then she applied for graduate school and earned a Master’s degree. She finished school in 1999 and took a job as a mental health counselor. Soon after accepting the position and on the advice of her neuropsychologist Shelly informed her employer about her brain injury. Of this, Shelly said:

That was the worst thing I could have ever done, ...because they put it against me. So I got my foot in the door, started working there right after graduation, and let them know about my TBI. ...My first supervisor started coming down on me. ....He would give me all of his hard clients that didn’t like him. ...I said, ‘That’s fine. I love the challenge. I like his clients. Keep them coming!’ He didn’t like that attitude, [so] he just doused me with all of this psychological assessment stuff. That was no

problem, but the worst case scenario came when he kept telling me that I was doing all of these things wrong when I was doing them correctly. ...

Was it the TBI, or was I being forced out because I was liked there? I don't know. I basically left ... of my own volition [so I could] survive.

Shelly was there five and a half months.

Shelly then had a succession of jobs over the next several years. First, she took another mental health job that she kept for one and a half years. She quit that job stating that she was over-worked and "had no outside life." Next, she took a job as an outpatient therapist at a mental health clinic; however, eight months later, the grant she was working under ceased, and she had to find other employment. She then took another job as an outpatient therapist. In this position, she believed her employers were conducting their business fraudulently, and, when she questioned them about this, they fired her after only nine months with the company. Shelly believed she was "an easy target" for the employer because of her TBI and because she was unmarried. She filed a lawsuit but was unsuccessful in winning her complaint.

Shelly's next job was an in-house therapist staff supervisor. Again, Shelly stated with a smile, "Loved the job, hated the upper [management]. I got along well with everybody. The clients I loved [and] they loved me." Shelly held that position for 8 months, but she felt that her supervisor did not like her and was "badmouthing" her. She also stated that the supervisor was violating her privacy and undermining her work by telling clients about her TBI. At the end, Shelly said that her co-workers "said they would

stand up for me, but, of course, they had to ...[watch out] for their own backs. They were all against me the day I was fired. What are you going to do?”

Shelly’s next job was as an inpatient therapist. Shelly was unsure how long she worked there but stated that she had problems with her supervisor due to ethical issues and was eventually fired. Following this incident, Shelly took a “temp” position with a state-funded organization filling in for workers while they were absent. She enjoyed the variety of this job and liked the people with whom she worked. She spent approximately one year there. Her next two jobs were not as a mental health counselor but were in the administrative assistant realm. She spent approximately one year at each position. Of these she said, “I didn’t care for [it], but you make the best of everything you do. I am not a secretary, but hey, it’s a job. It’s a way for me to continue living and existing.”

Shelly estimated that she has held 12 jobs since her injury. She stated several times that she would still like to work as a mental health counselor but only for a reputable establishment. She also stated that she has “applied many times [at Vocational Rehabilitation], but they won’t hire me.” Shelly currently works as a grant coordinator. “I’m glad that I [took the job], because I have been able to do a lot more stuff with TBI than I expected or anticipated.” When asked if she enjoys her work now, Shelly said, “I love it. Yes. I’d rather be counseling also and advocating for people in a bigger way, but hopefully this [job] will lead to [that].”

Gail stated her belief that Shelly’s trouble with jobs has been that her employers hold her TBI against her. “Although other people made mistakes—like everybody does—...it was no big deal. ...[But] in the workforce, [Shelly] didn’t have a chance.” When

asked whether she thought employers singled her daughter out because of her brain injury, Gail stated, “That’s putting it mildly. ... [She’s] abused.”

*Strengths.* Shelly displayed multiple strengths that had emerged post-injury and detailed ways in which her injury had actually benefitted her. Gail discussed a positive outcome from the injury as well and described her daughter’s personality traits of compassion and resilience.

Shelly displayed a positive attitude throughout the interview. When discussing her challenges, she said, “You just do your job to the best of your ability, and you move on if you need to.” Shelly also talked to the researcher about the positive aspects of her injury: “I wasn’t able to stand up for myself before injury. After injury, I was. I think I gained so much more from the injury that I’d hate to see myself without an injury, what I’d be like. I think I would still be very passive and not...advocate for others. So I think it was a very good thing for me.” Shelly’s mother confirmed the notion that positive changes resulted from the injury. She explained that the injury made Shelly “more aware of being happy with yourself or what you are and not what people expect of you.” Gail listed several positive character traits she observed in her daughter:

She’s very humble, very modest. She doesn’t take credit for much. ...Her strong points are compassion for her job [and]...for the people that she’s worked with; ...understanding, because she’s been there. ...Nothing else can compare when you’ve been there and done that. She is constantly listening and encouraging, but she understands where [other survivors] are at ...[and] that they need this help.

She tries to find them the right people to go to, the right places...when they're absolutely [as] lost as was she."

Shelly described the passion she felt for assisting other survivors of brain injury. She said: "It hurts me so bad to see [survivors] unemployed. I will definitely advocate for anybody at their [sic] job facility. ... I am hoping I can become more successful at that, so that I...am able to train others how to do that successfully...and also to work with employers in a better manner, because...it is so important."

Finally, Gail discussed Shelly's accomplishments and the fact that, shortly after the injury, she did not think Shelly's recovery would be as successful as it had been. Gail talked about questioning Shelly's decision to go back to school and study mental health. When Shelly told her mother that she wanted "to help other people [the way people] have helped me," Gail admitted to having "spent the day crying, because she had such lofty goals. ...I didn't take her seriously at all. I thought that was part of her head injury. It made me so sad, [but] she did it! ...I'm fascinated and so shocked she got this far, but she's worked extremely hard at coming back."

*Strategies.* Shelly and Gail described several tactics and tools Shelly has used to be successful in the work place. These included personality traits—such as tenacity and a willingness to accept the support of others—and compensatory strategies—such as implementing external memory aids and organizational supports. The informants also spoke about strategies Shelly has used to cope with the emotional aspects of being a brain injury survivor.

Shelly spoke of persistence and utilizing the help of others as two characteristics that have contributed to her successful return to work post-injury. She said, “I try and do it as best as I can for as long as I can, until I get so frustrated, and there is no way I can figure it out. I finally come to that decision [but], it could be weeks later. ...That’s when I start asking for help. I know I can’t do everything on my own, so that’s when I have to pull in resources.

Shelly also discussed her use of calendars as an external memory aid and her strategy of taking “lots of notes” as being essential to her success. She explained: “I always use a calendar. I’ve got my work calendar, and the calendar that I bring with me everywhere. Most days I don’t have to use it, but, if someone wants to know a certain date ...I have to look at that calendar.” Even though her memory has improved, she continues relying on calendars and writing things down, because she knows her memory “is never going to be the same” as it was prior to injury. Gail confirmed that “notes” were crucial to help Shelly stay organized and commented that Shelly “is great on organizing her schedule.” As another example of using organizational supports, Gail explained how Shelly prepared for trips. She said, “If she is going somewhere farther away, she maps everything out. ...She gets on the Internet and maps out exactly which roads to take. She works in the extreme that way, but it’s her coping skill. ...Thank God she learned those [sic].”

Shelly discussed how she has coped emotionally with being a survivor of TBI. She reiterated again that “you just have to deal with it the best you can, move on, and that’s it.” She reported trying to guard against blaming negative events on her brain

injury, instead adopting the attitude that “I need to change something [when] things are going awry.” Shelly also reported that she used running and exercise as emotional releases: “I ... wake up at four every morning to do my PT, and then I do my exercising and weight lifting, and then I go to work. ... To me that has helped emotional-wise.” Shelly also stated that running helped her overcome her fatigue: “Lack of energy [was a problem] for a long time, but then I got right back into running, which to me was my biggest asset.” Gail confirmed Shelly’s use of exercise as a coping mechanism: “[Running] is how she claimed she got through the entire thing. ... [It is her way of] letting off steam. It rejuvenates her.”

“*So Mad*”. Gail disclosed some of the problems her family faced after Shelly’s brain injury. She spoke about Shelly’s younger sister and the difficulties she experienced as well as how Shelly would have angry outbursts at times. She also spoke about how furious she still is about the nature of the incident that caused Shelly’s injury.

Gail stated that Shelly’s younger sister suffered greatly after the injury. She was 16 years of age when Shelly’s injury occurred and suffered bouts with an eating disorder after the incident. Once, when Shelly was still hospitalized, Gail and her husband were literally feeding both of their daughters: Shelly needed assistance eating and they were trying to force their youngest child to eat as she battled anorexia.

Shelly’s outbursts of anger had negative effects on family relationships. Gail provided an example of a time when Shelly was recovering from the accident and had a verbal altercation with her: “I didn’t blame it on her being rude to me. I blamed it on the injury.” Low frustration tolerance prompted Shelly to take out her anger on her mother or



younger sister. Shelly acknowledged that such incidents made her “feel horrible” but still occurred occasionally. Shelly said, “I still find myself venting on [my sister], which is not right.” Gail reported that Shelly and her sister “didn’t get along for years after this thing happened, but now they’re very close.”

Gail described her intense anger at the situation, the people involved, and the circumstances surrounding her daughter’s attack almost 19 years ago. When the researcher commented that Shelly did not express similar anger, Gail retorted:

She’s a silly girl. She has said since...maybe [1993] ‘Mom, ...there is a reason this happened to me. God has a plan for me.’ And she still says that. Occasionally I say, ‘Why doesn’t he speed things up already?’ What the hell? How can you hold on to that? But that’s what she put in her head, and she’s not changing her mind on that one.”

Gail complained that Shelly’s attacker “never apologized.” and that she is still angry to this day, that Shelly never received monetary compensation.

**“Wade.”** Wade was 29 years old when he was involved in a single-car accident and sustained a severe TBI. He remained in the hospital for two weeks to treat his medical complications and then spent 4½ months in a rehabilitation hospital. According to his father, Wade’s coma lasted 82 days. After discharge from the rehabilitation hospital, he spent 1½ years at a transitional living facility to receive additional rehabilitation services. He then moved to an assisted living apartment within the same facility and was living there at the time of the interview. The interview occurred when Wade was seven years, eight months post-injury.

Wade was working as an assistant engineer for an architecture firm at the time of his injury. He had attended college but had not earned a degree. He had held four jobs prior to injury, including working as a heavy equipment operator and performing diesel mechanic work. He had not returned to paid employment following injury but held two volunteer positions at the time of the interview.

Wade's data corpus for this project included two interview transcripts—one from Wade's interview and the other from a joint interview with Wade's parents, Jacob and Jane—photographs, a document written by Jane to Wade while he was unconscious, and observation notes taken by the researcher. The researcher identified six themes and two subthemes from the data corpus. The six themes were: (a) *Effect on the family*, documenting the emotional strains faced by family members during Wade's recovery process; (b) *Work*, including descriptions of Wade's post-injury volunteer positions and the beliefs Wade and his parents held about work for TBI survivors; (c) *On-going challenges*, documenting struggles Wade continued to face; (d) *"Just slit my throat,"* detailing the personality changes Wade experienced since his injury; (e) *Strengths and Strategies*, describing factors that contributed to Wade's post-injury life and success with volunteer employment; and (f) *Activities, social life, and support*, providing information about Wade's current hobbies and friendships. The *Effect on the family* theme included one subtheme: *"Wants and needs,"* documenting the effect of the financial changes on Wade and his family. The *Work* theme included the subtheme, *Ideally*, that explained the parents' perspective about the ideal work situation for Wade and their wishes for more employment opportunities for their son as well as other brain injury survivors.

*Effect on the family.* Wade's family had many negative experiences and emotions subsequent to his injury. While initially hospitalized, they feared he would die. They made difficult decisions, faced repeated disappointments, and took legal action to become Wade's guardians. Since the completion of formal rehabilitation, and despite a relatively good recovery, Wade's parents had to take a more active role in his life than they had prior to injury. In particular, they had to manage his finances, which resulted in negative feelings and minor altercations among family members. Additional details regarding this family interaction appear in the subtheme, "*Wants and needs.*"

Wade's injury was severe. Although he had no recollection of any of the events occurring immediately post-injury, Wade explained to the researcher that doctors "were preparing my parents for the possibility I might live the rest of my life as a vegetable." The doctors reportedly gave Wade only a 5% chance of survival and wanted an immediate decision from family members about what efforts to expend to keep him alive. After a period of coma followed by a prolonged state of impaired consciousness, one doctor advised the parents to insist that Wade have an operation to put a shunt in his head. Following this successful operation, Wade began emerging from impaired consciousness within days.

Wade's parents talked about the disappointment they felt when Wade's therapy was finally discontinued, because they knew his progress had likely reached a plateau and began to understand the long-term effects of the brain injury. Jane stated that she would have liked to see him get more physical therapy and speech therapy. They also talked about the legal troubles they experienced with becoming Wade's guardians and how

difficult it was to get information about him from medical staff due to privacy laws and policies.

The subtheme “*Wants and needs*” documents Wade’s parents’ report that they possessed a different relationship with Wade than with their other children. Part of this difference stemmed from their involvement in providing Wade with spending money every month. Because some of Wade’s friends seemed to have a “limitless financial situation,” Wade often wanted more money than the allotted amount provided by his parents. His father speculated that the primary motivation Wade would have for obtaining paid employment would be to increase his access to spending money. He explained:

Well, I think he would want a paid position only for the money. ... He understands that his limit now is 80 bucks a month. That’s all he gets to spend ... and, ... if he sees something, he wants it. We’ve had lots of arguments ... over and over again about this. ... He really gets upset, because he wants something, and he knows he can’t afford it. He just goes ballistic.

Likewise, when asked about the main difference between his life now versus his life prior to injury, Wade stated, “[I’m] having to really ... concentrate and [categorize] wants versus needs; my life is monetarily so much different.”

*Work.* Wade attempted several times to obtain paid employment following his TBI, but these attempts were unsuccessful. The participants discussed the details of Wade’s volunteer positions and speculated about barriers that had impeded Wade’s return to work. Finally, they commented on comparable barriers that they assumed other survivors of brain injury would face regarding the obtainment of gainful employment.

Several beliefs about the ideal working situation for Wade appear in the subtheme *Ideally*.

Wade had held his current volunteer positions, at a nearby YMCA and an insurance office, for about five years. He performed janitorial duties and claimed to enjoy the work, saying, “I built good relationships there.” He worked a total of three to five hours each week, alternating weeks between the two facilities. He obtained both positions with the assistance of others.

Prior to accepting his volunteer positions, Wade reported filling out several job applications after moving to the city in which he currently lived. He believed he failed at obtaining employment, because he did not have a driver’s license. Later in the interview, Wade expressed his belief that he had the necessary skills to work. For example, when referring to a nearby store, he said, “Trust me; I more than qualify compared to some people who are working [there].” Despite such comments, Wade could not provide any specificity about the type of work he wanted to do other than he liked to work with people. Post-injury, Wade had never advanced far enough in the job-seeking process to have an interview. Wade stated later in the interview, “I firmly believe and feel that if I was to wake up and have a job next week that I would be fully capable of performing that job”; however, he then mentioned several barriers to performing job tasks such as the inability to drive and do heavy lifting as well as his short memory problems. Similarly, Wade stated that at his current jobs his biggest frustration was struggling to remember people’s names.

Likewise, the researcher also asked Jane and Jacob to think about the challenges their son might incur in a paid employment setting. Jacob cited several examples of why he felt Wade would experience interpersonal problems, and Jane spoke about her son's physical challenges. Wade's father explained that Wade would likely get upset with a fellow employee. He stated that Wade had had several minor altercations with fellow residents "over little things that [usually] wouldn't be a problem," such as someone removing hot sauce from Wade's table in the dining area. He continued, "I would say things like that might interfere with his work and relationships with other employees." Jane stated that Wade loved his volunteer work, and that it provided him with a sense of pride. On the other hand, Jane noted that Wade experienced frustrations because his aptitude was high but he simply was unable to do his pre-injury work because of the physical limitations he had experienced subsequent to his brain injury. When asked if they foresaw Wade working in a paid position or maintaining volunteer work in the future, his father said,

I've talked to several people ... about that. ... I think there's just not the jobs out there that ... disabled people like him really need and could benefit from. ... I think that the brain injury scenario [is difficult]. ... Employers have probably tried people like that before [and it] hasn't worked out, so they shy away from that. I can't blame them ... to be honest with you.

Jacob, referencing the difficulties of another brain injury survivor they knew, explained that he felt many survivors had interpersonal problems in the work place that made them unsuccessful with employment ventures.

Wade also commented about survivors in general going back to work. He stated that a survivor's first obstacle was their capability, followed by their motivation. He spoke highly of volunteer positions and seemed to encourage this type of work for survivors unable to hold paying positions. He stated that volunteering "gives [survivors] a sense of purpose ... [and] a sense of being back in the workplace," he continued, "and it may remind them of what they enjoyed about their work before injury", encouraging them to appreciate what they have rather than ruminate about what they have lost.

Additionally, Wade's parents had several opinions about ideal employment situations for Wade and other survivors. These opinions were documented in this subtheme *Ideally*. Jane again mentioned Wade's physical limitations and stated, "I do think ... he would be able to do [a] job with his mind but not with his body." Further, she gave the example that even now Wade could talk his father through fixing something over the phone but that he could not actually do it himself. Jacob concurred, stating that prior to Wade's accident he was an efficient worker. Jacob believed Wade's mind still processed information quickly, but his body could not keep up. Jane then gave her opinion on the ideal work situation for her son, stating that it would be best if there were a position where he was the "mind" and someone else was the "body" performing all of the physical tasks for Wade. Likewise, she said that she wished the facility where Wade resided had a connection with local businesses to arrange employment opportunities: "[I

wish] that they could have these ideal jobs somewhere out there for their residents, but I know that's impossible."

*On-going challenges.* In addition to the work challenges cited by Wade and his parents, Wade continued to struggle with other on-going challenges. Among them were physical issues including his inability to drive. Wade and his parents spoke about sensory, memory, and emotional issues as well.

Both Wade and his father discussed Wade's balance problems. Wade stated that he often had to adjust the way he performed certain physical tasks, implying that he was more likely to get hurt since his brain injury than he was before. Furthermore, they both discussed the extensive nerve damage in Wade's right arm and the fact that prior to injury he was right-handed. Jacob stated, "His writing ... is still not very good. ... If he has to use his right arm, he has learned to pin it against his body so it doesn't shake. ... As far as physical challenges, those are the main ones." Likewise, Wade stated that his "second biggest challenge" was that he used to be right-handed, and he had to "retrain" his left hand. Wade stated that his biggest challenge, however, was not being able to drive. Regarding his driving capabilities, his father explained that it would not be safe for Wade to drive because of an injury to his knee and slowed reaction time. "I think that ... probably ... the most frustrating thing since the accident [is that] the wheels still turn up here but not anywhere else," Jane said of Wade's good cognitive skills paired with his physical limitations.

Jacob stated that Wade no longer had a sense of smell. Additionally, both Wade and his mother talked about his vision problems. Wade stated that he never wore glasses



before his accident but needed them afterwards: “I [had] really bad double vision [after injury]. If I don’t concentrate right now you have four eyes.” Wade explained that he still wears prism glasses to correct his visual deficits.

All three participants discussed Wade’s memory problems. Wade stated that it was often hard for him to remember what people said when engaging in conversations. He had similar problems with remembering written information: “I don’t ever read a book anymore, because it’s hard for me to remember what I read the night before.” Regarding phone conversations, Jane specifically stated that Wade would often remember only part of the information discussed.

Finally, Wade and his parents talked about the emotional changes they had noticed in Wade. Jane stated that he was more likely to cry since injury, and both parents discussed Wade’s emotions in conjunction with his tendency to perseverate on ideas. Wade’s father stated that when things do not go as Wade would like them to, he became upset. Jacob added that Wade had “a tendency to channel his thoughts in one direction and stay there until the last dog dies. ... He’s on that topic no matter what.” Additionally, Jane and Wade noted that the time of day often affected Wade, stating that he thinks more clearly and gets along with others better earlier in the day. Wade reflected that later in the day, “I seem to get a little more hard to deal with. ... I get a lot less open-minded ... and a lot [more] irritable about things that normally wouldn’t bother me or shouldn’t bother me.”

*“Just slit my throat.”* Wade experienced many emotional changes after injury. His parents talked about how different his attitude was toward life in general. Jacob

relayed a conversation Wade had had with a family member prior to his accident. Reportedly, Wade had stated that if something ever happened to him and he became disabled "... just slit my throat because I'm not gonna live like that." Jacob continued, "So we were concerned during his whole recovery process how he would handle being disabled." Wade was in fact in a wheelchair for a number of months. "So we were concerned about his inner thoughts about that situation. Contrarily, Wade's parents suggested that Wade is very happy with the facility in which he resides. Jane added, "To me, he's handled it better than the rest of us. ... We thought he would be angry and bitter and resentful, and he's not."

The researcher asked Jacob and Jane the biggest change in their son since his injury. Jacob again mentioned Wade's attitude transformation. Both of Wade's parents confided that he attends church regularly, whereas before injury he did not go. Jane stated that she believes his faith has helped him with patience and understanding. According to Jacob, "He was kind of self-centered before. I think he has a lot more purpose [now]. [Before, he was just flying by the seat of his pants ... spend what you can, drink what you can.

*Strengths & Strategies.* Wade and his parents talked about his personal strengths and the strategies he used to compensate for his ongoing challenges. All participants cited Wade's long-term memory as a strength for him, as well as his independence with appointment scheduling and problem solving capabilities. Wade and his mother both discussed how Wade compensated for his short-term memory challenges and other work related issues.

Wade stated that his long-term memory was intact. Jacob concurred, “As far as his long term memory, he remembers things just like he did before. ... He’s got a better memory than we do actually.” Wade’s father described him as “a thinker” and explained that he always did well in school without studying.

Additionally, Jane stated that Wade was independent as far as scheduling personal appointments and activities. She stated that he made all his dentist, doctor, and eye appointments himself and arranged his own transportation. He also independently arranged to get to church and back every Sunday. Jacob agreed, “He takes his own medication, and he’s almost like clockwork.”

Wade and Jane cited ways that Wade compensated for his poor memory. “He has a white board [where] he keeps track of ... stuff,” Jane stated, adding that at times Wade would put reminder notes in his devotions that he read daily. Wade explained that when he first started working at his volunteer position at the insurance office, he asked his supervisor to make a list of the tasks for which he would be responsible. Likewise, he reported using the same strategy when he started at the YMCA: “I made ... myself a little list I kept in my wallet ... [of] what my duties were. ... It took probably four or five times to get it all down pat.” As for other strategies at work, Wade explained that he had to adjust the way he mopped the floor to overcome his challenges with balance.

*Activities, social life, & support.* Wade resided in an assisted living facility and was unable to drive; however, he continued to participate in activities. He enjoyed an active social life and had a tight-knit support group made up of friends and family members.

Jane stated that his hobbies include riding his three-wheeled bike and rewiring electronic devices, adding that she was grateful he participated in activities that were stimulating. Jane and Jacob discussed how much they liked the facility where their son resided and the wonderful opportunities it had provided him. Jane said: "He does have some awfully good friends there. ... There's staff members, too, that take him places. ... They go to concerts ... [and] to ball games. There's [sic] several families that include him in their [activities]." Wade had several friends he had met since his injury, most of whom lived in the facility where he resided. Wade also retained some pre-injury friendships, stating that they now treated him the same as they did prior to his injury. Of his pre-injury friends, Jane stated, "I've been really surprised that they've stuck around. He's really fortunate."

The researcher asked Wade how his social life has changed since injury, Wade stated of his friends that: "it depends on them involving me ... [providing] transportation for me, ... 'cause they got [sic] families and ... busy schedules. They gotta *want* to help me." Wade stated that his friends involve him in their lives and cited the many football parties he has attended as an example. He also explained that in addition to his friends, he saw his coworkers and employers outside of work. At the insurance office, he works for his cousin and they have lunch together at times. The YMCA employees invite him to their Christmas party every year. Jacob stated: "We always joke that except for his disability, he has a better life than we do. ... We go to work and we come home and pay bills. ... He goes out!"

Finally, Wade talked highly of the support people in his life: “I firmly believe [for] anybody [who] goes through this [or] through any injury, ... one of the most important things ... is to have ... great support. My family always offered me support. And [my] friends.” Wade confirmed Jane’s observations that he had made several good friends since injury, as well as maintained some pre-injury friendships. He mentioned that he lost several pre-injury friendships as well and added: “But that’s one of the good things. ... It lets me know the difference between people who I thought were my friends and the people who really were my friends.”

***Cross-case results.*** The initial section in the cross case-results is *Employment status*. Several factors provided a means of comparing survivors in terms of their employment conditions. The researcher pieced this information together from several different sections throughout the qualitative data corpus. The majority of this information was derived from background information was therefore not considered thematic content. Following *Employment status* is a section devoted to describing the *Cross-case themes*.

***Employment status.*** Several differences existed between the five survivor participants pertaining to employment status. These differences included: (a) whether the survivors resumed their pre-injury jobs, (b) whether they maintained their pre-injury jobs up to the time of their interviews, (c) whether they were employed or unemployed at the time of interviews, (d) how many job positions they had held since injury, (e) the length of their current employment, and (f) the level of assistance they required at their current job positions.

Bob, Carl, Sara, and Shelly returned to their pre-injury employment positions within a four-month post-injury period. Of the four, only Carl and Sara were successful in maintaining their job position and were still working at their pre-injury jobs at the time of data collection. Carl and Sara differed in the length of time they had held their jobs since injury and in the level of assistance they required to maintain this employment.

Specifically, Carl had maintained his job for approximately 9 years since injury, whereas Sara had maintained her job position for 2 years since injury. Beth, Carl's wife, helped Carl with a substantial portion of his work; in contrast, Sara needed some accommodations after returning to work (i.e., discontinuing travel and no longer writing specifications for software) but otherwise was independent and did not require assistance with her other job tasks.

Bob and Shelly returned to their pre-injury jobs but did not maintain them following injury. Both of their employers fired them from their positions, and they both believed their terminations were unfair. Bob never returned to the work force following his termination, neither to paid nor volunteer work. He had only searched for jobs in his pre-injury job field and, at the time of data collection, had been unemployed for approximately two years. On the other hand, Shelly returned to paid employment after her termination. She had held approximately 12 different positions between the time of her injury and the time of her interview. These positions were in a variety of fields, and Shelly cited a number of problems regarding her former places of employment. She had been in and out of the workforce through the 18 year time span since her accident. Shelly spent 7 of those years in college obtaining a second Bachelor's degree as well as a

Master's degree. The longest she had maintained one job since injury was at her current place of employment. She had been working as a grant coordinator for approximately 3½ years. Shelley reported that she was independent in completing her work duties, and, thus, the researcher considered her as needing no assistance.

Finally, Wade was the only survivor who never returned to his pre-injury work. In fact, Wade did not return to any paid position after injury but had enjoyed two volunteer positions, holding each of them for about five years. He accepted these positions approximately two years after his injury. At the time of the interview, he reportedly did all of his janitorial tasks at these jobs with no assistance.

***Cross-case themes.*** Five to seven themes, including subthemes for a select few, emerged through the Phase II analysis for each of the five participant cases. Comparison across survivors revealed both similarities and differences among themes and subthemes. The comparative analysis revealed that 5 cross-case themes were consistent across the cases. These were: a) *Challenges*, b) *Strategies*, c) *Work-related issues*, d) *Social and personality changes*, and e) *Effects on the family*. Table 6-1 displays the case study themes for each survivor under the corresponding cross-case themes. Of note, one survivor (i.e., Bob) did not have a case study theme relating to the cross-case theme of *Effect on the family*. Possible explanations for this include: (a) that this was not a pertinent issue for this particular case, (b) that Bob's presence for the entire interview inhibited his wife from talking about negative effects her husband's brain injury had on her or other family members, and/or (c) the relative recency of Bob's injury precluded his or his wife's awareness of family effect.

Table 6-1

*Survivor's Case Study Themes and Subthemes corresponding to the Cross-case Themes*

	Challenges	Strategies	Work-related issues	Social & personality changes	Effect on the family
Bob	<i>Challenges at work &amp; "Nowadays"</i>	<i>Strategies</i>	<i>"I did not go back to my old job," "They tried to hire me for 25 years," &amp; "I should have connected the dots"</i>	<i>"Chasing cars"</i>	---
Carl	<i>"They get really nasty," On-going challenges, &amp; "Just old age"</i>	<i>Strategies</i>	<i>Back to work</i>	<i>"Was that before or after the accident?"</i>	<i>"Nobody would have known"</i>
Sara	<i>"Mommy's head hurts" &amp; "I'm gonna go in the closet"</i>	<i>Strategies</i>	<i>"I just have a head injury. I'm not contagious" &amp; "Suck it up and quit complaining"</i>	<i>Strengths</i>	<i>"You have to fight if you want to get better"</i>
Shelly	<i>Challenges</i>	<i>Strategies</i>	<i>Job history</i>	<i>Strengths</i>	<i>"So mad"</i>
Wade	<i>On-going challenges</i>	<i>Strengths and strategies</i>	<i>Work</i>	<i>Activities, Social life, and Support &amp; "Just slit my throat"</i>	<i>Effect on the family, ("I was thinking death"), &amp; ("Wants and needs")</i>



The content from only three of the cross-case themes—that is *Challenges*, *Strategies*, and *Work-related issues*—were directly pertinent to the central research question concerning the post-injury employment experiences described by TBI survivor participants and those associated with them; thus, only details about these themes appear in the following sections.

*Challenges.* Each survivor had challenges pertinent to work as at least one of their themes and/or subthemes. The challenges experienced by survivors were diverse, but all challenges documented in the following sections either affected or potentially affected their employability or ability to perform work duties. Generally, the information contained in this section includes sensory and physical deficits, cognitive problems, and emotional issues.

The participants discussed multiple sensory and physical challenges that the survivors faced and that had the potential to affect employment. All of the survivors, according to their report or that of their loved ones, experienced vision problems. Regarding other sensory deficits, Wade appeared to have the most substantial challenges. Specifically, he had lost his sense of smell and feeling in his right arm due to extensive nerve damage. Four of the five survivors cited physical deficits subsequent to their brain injuries. These deficits included balance problems, paresis, and other medical issues. These deficits often prevented survivors from performing activities they carried out prior to their brain injury. Shelly, Wade, Sara, and Carl all noted balance problems, and, although Shelly's and Sara's had subsided, Wade and Carl cited balance as an ongoing challenge. Wade could not use his right hand or arm, subsequently forcing him to rely on his left hand for most tasks. Shelly had suffered

many subsequent medical problems throughout the years due to the nature of her injury but, at the time of data collection, was having physical problems that prevented her from running regularly. Although the survivors and their family members mentioned several sensory and physical problems, they rarely cited them as the most troublesome with regard to employment issues; instead, the most problematic deficits were often those that were cognitive or social/emotional in nature.

Cognitively, the survivors and their family members cited memory and executive functioning skills as problematic. The researcher noted that a lack of awareness also played a role in several of the survivors' and/or their family members' frustrations. All survivors and/or family member participants stated that long-term memory was intact but that short-term memory was an ongoing problem. Several survivors mentioned that remembering people's names was particularly difficult. Shelly experienced planning and organizational deficits, as well as concentration and attention issues. She cited more difficulties with executive functions than did the other survivors. This may have been due to a greater awareness of deficits as a result of her being the longest time post-injury and her having worked with other survivors. Two of the survivors seemed to have problems with distractibility. Specifically, Gail stated that Shelly was more sensitive to bright lights and loud noises than she had been prior to injury, and Sara reported sensitivity to extraneous noise and activity. Similarly, Sara mentioned that co-workers conversations distracted her in the workplace.

Bob cited problems with understanding where and how to access necessary items on his computer but did not note other work-related challenges. The researcher

felt that Bob reported few problems in the workplace because of his lack of insight into his deficits. His wife, Colleen, had little insight on this subject as well, because she was unsure of his work responsibilities. However, Colleen mentioned that Bob had difficulty initiating tasks around the home. Therefore, initiation was likely a problem at work as well. Similarly, Carl's wife noted challenges with task initiation and stated that Carl spent a great deal of time talking about what he was going to do but rarely followed through. Shelly spoke about a lack of awareness she displayed throughout her recovery. She made several comments suggesting some of her former problems may have resulted from her impaired awareness.

Both Bob and Carl's behavior during their interviews suggested they lacked awareness or insight into their deficits. Carl did not acknowledge any emotional deficits, which his wife noted as the biggest change since injury. Carl did not acknowledge his difficulties with math and the paperwork aspect of his job either, which his wife took on after his injury and was still completing at the time of interview. A lack of awareness was not apparent to the researcher during either Sara or Wade's interviews. However, Wade stated that he felt the main reason he did not hold a paying job was because he did not have a driver's license; however, later in the interview he acknowledged that his short term memory problems and his physical deficits were barriers to paid employment as well as his inability to drive. The inconsistencies Wade expressed may be representative of Wade's lack of awareness.

Finally, the survivors all had some sort of social and/or emotional challenges. The decreased ability to socialize with others appeared to limit their interactions with supervisors and co-workers. Depending on the job, a lack of social skills may have

negatively affected a survivor's performance of necessary tasks. Inappropriate emotional expression was a problem for several survivors as well. Shelly and her mother, Bob's wife, Wade and his parents, and Sara discussed an increase of emotions or emotional expression since injury. Most of them reported greater emotional lability post-injury, specifically in the form of increased crying. Carl, however, was an exception to this. Since injury, he demonstrated decreased sensitivity and had lost all emotions except anger, according to his wife. She noted that Carl was fortunate to have a self-employed position, because employers would likely not tolerate his post-injury anger outbursts and tendency to hold grudges. Sara spoke about her decreased tolerance for noise and activities, citing that she had trouble tolerating her children's behavior at times. Shelly and her mother also spoke of Shelly's frustration level being less than it was prior to injury and her tendency to engage in verbal disagreements with family members. Wade's parents noted that, if Wade did have a paid employment position, they feared he would have altercations with other employees or employers, resulting in his termination. Wade explained that his decrease in frustration tolerance often precipitated the engagement in frequent verbal arguments with others. Wade acknowledged often getting angry despite knowing that he should not let small things bother him.

*Strategies.* The survivors had one theme from their case study that included information specifically about strategies (refer to Table 6-1). The strategies used by the survivors were tactics designed to compensate for deficits in the workplace. Four of the participants spoke about the memory strategies, organizational tactics, and

physical modifications they used to aid their completion of work tasks. Carl's wife, Beth, noted his refusal to use compensatory strategies.

The majority of strategies utilized by the survivors were to compensate for memory deficits. For example, upon returning to work, Bob wrote notes and left them where he would be sure to see them. Likewise, he wrote important information in a notebook as a memory compensation strategy. Shelly also reported her use of note-taking and keeping a notebook for work. Sara mentioned note-taking as well and stated it was not something she had done prior to her accident. Wade noted that when he began working at his volunteer positions, he required a list of tasks to complete. Wade made this list himself and kept it in his wallet. At the time of interview, he no longer needed it, because he had held the positions for several years. Both Sara and Shelly cited the use of a planner, stating that it was not something they used before injury but was a necessity now.

Sara and Shelly noted their need for organizational tactics, and Shelly's mother confirmed Shelly's use of the computer for organizational needs. Sara was the only survivor who mentioned use of technology as a strategy. She noted that she bought a new phone to help her with organization. Sara mentioned using a computer calendar in addition to the planner she carried with her. Sara was the only survivor who used headphones at work to block out extraneous noise. Wade was the only survivor to use a strategy to compensate for a physical deficit; specifically, he adjusted the way he mopped at work due to his lack of balance.

Finally, Carl was the only survivor that reportedly did not use compensatory strategies. His wife explained that Carl felt he did not need them. When asked

specifically about a calendar, he told the researcher that he and his wife try to utilize it for appointments. He added that the reason he needed to use the calendar was likely because of his age and not his brain injury.

*Work-related issues.* The participants noted several other additional employment factors, most of which were unique to the particular survivor and were not shared among other survivors. Among these issues were changes in work responsibilities, issues relating to job satisfaction, and biases experienced by survivors in the workplace.

Bob was the only survivor who noted an extreme change in responsibilities upon returning to work. He was in a different office with different duties after injury. He reported that he had no support or training to aid him in completing these new duties. He and Colleen also commented about the drastic change in Bob's relationships with his supervisors before and after injury. Bob's employers no longer spoke to him or Colleen. This was in contrast to their weekly telephone calls to Colleen inquiring about Bob's progress during his initial hospitalization.

Likewise, Carl and Sara both had some job responsibility changes after returning to work. Carl was no longer involved in insurance claims, and Sara no longer traveled for her company. Sara also ceased writing specifications for software, as she had done previously. Although not directly mentioned by Carl, his wife had taken over the paperwork tasks of his job, and he was only responsible for visiting his clients and being a "liaison" between the clients and the company.

Sara was the only survivor to report less job satisfaction after returning to work than she had experienced before injury. She felt her employer no longer utilized

her as much as she could, and Sara cited boredom as a problem at work. On the other hand, Sara also was the only survivor who acknowledged that she was fortunate for her salary and flexible hours. Sara and her mother reported that Sara was well taken care of at her place of employment while she was recovering, noting that they did not force her to use her accrued vacation days. In terms of relationships, unlike Bob, Sara felt her employer and colleagues treated her the same after returning to work, although she noted that initially her co-workers were a bit “stand-offish.” Additionally, she noted that the relationship between her and her direct supervisor did not change. Likewise, Carl’s relationship with his supervisor did not change, although Nancy noted that Carl seemed more “chatty” than he was prior to injury.

Shelly and Bob both reported mistreatment at work due to their brain injuries. Bob felt a general lack of support and believed his termination was unfair; his wife concurred. Shelly and her mother reported that Shelly “was singled out” because of her brain injury and Shelly reported that she made a mistake when telling her supervisors that she was a survivor. She stated, “That was the worst thing I could have done.” Clearly, Shelly had the most extensive history of post-injury work-related experiences, as she was the survivor with the most time post-injury. Shelly was also the most passionate about her job and seemed to be the most content with her current position. Wade, the only volunteer worker, was different than the others in terms of lack of payment for his work. Despite this fact, he enjoyed his job and mentioned that survivors who could not hold paying jobs should volunteer, because it gives people a “sense of purpose.”

## **CHAPTER 7**

### **Discussion**

The results from this study indicated five major findings. First, when comparing the quantitative and qualitative data sets the researcher noted a lack of synchronicity between survivors' PIES scores and their qualitative results regarding work satisfaction. Second, survivors' job satisfaction relates less to monetary rewards associated with paying positions than to participation in productive activities. This was evident in the finding that holding a volunteer or work position affected the quality of life survivors experienced, because it influenced the number and frequency of their interactions with others. Third, contrary to the belief that professional or administrative careers exceed survivors' capabilities because of high cognitive demands; survivors sometimes are successful in holding and maintaining such positions. Next, findings confirmed the notion that pre-injury level of education and the likelihood of obtaining post-injury employment are positively related. Finally, adjustments and accommodations to work tasks are often necessary for survivors to return successfully to jobs, and the implementation of additional strategies to aid survivors in independently completing work tasks seems imperative. The following sections of this chapter address each of these points. Following this are sections about study limitations and clinical recommendations.

#### **Employment Success and Job Satisfaction**

The researcher compared survivors' PIES scores, reflecting post-injury job success, and statements made during interviews regarding job satisfaction. Although she did not ask participants direct questions about job success, the qualitative data revealed



that survivors and their family members seem to define employment success qualitatively as job satisfaction. Rarely did the participants speak about extrinsic rewards obtained from working. In the rare case that participants mentioned pay or benefits, contentment with employment situations seemed more important and was discussed more often in the interviews. After comparing the quantitative and qualitative data disparities emerged. For some survivors the PIES scores accurately reflected their job satisfaction but for others it did not. The following section will explain the survivors' scores as well as the related confirming and disconfirming qualitative evidence.

Sara had the highest possible PIES score (i.e., 10); however, she expressed discontentment with her job. She was the one survivor who spoke directly about her pay as well as the convenient work hours she held, describing that these aspects should make her "suck it up and quit complaining," as documented in her theme by the same name. She stated feelings of boredom as well as being under-utilized at her post-injury job. Sara stated that before her brain injury she enjoyed her work. Carl, despite a high score of 9, seemed rather neutral about his employment position. Carl's PIES score was just one point below Sara's, but Carl did not speak about job his satisfaction the way the other survivors did. He appeared to be content with his position; however, his wife had taken over the work tasks that were most challenging for him such as filling out paperwork and doing mathematical computations. Shelly scored an 8 on the PIES and was likely the most satisfied of all the Phase 2 participants with her employment. This satisfaction was evident during Shelly's mother, Martha's interview. Martha stated that she had told Shelly that she worked too much, to which Shelly stated, "Mom, it's not really work if

you love what you're doing...This is my passion!" Thus, Shelly's employment satisfaction appeared to confirm her PIES score. Bob's PIES score also seemed to match his level of satisfaction. Bob was clearly the least satisfied with his employment situation, and scored a 3. Bob and his wife both discussed his disappointment with his unemployed state, and the fact that following his injury he had been unable to acquire even an interview. Wade's job satisfaction, on the other hand, did not match his PIES score (i.e., 2). Both Wade and his parent noted on several occasions that Wade enjoyed his work, yet Wade had the lowest PIES scores possible for this study.

One possible explanation for the variation of findings between employment satisfaction and PIES scores may be that the survivors who were further post-injury appeared more satisfied. Shelly and Wade, the seemingly most content, were more than eighteen years and more than 7 years post-injury, respectively. Wade's father suggested during his interview that Wade might have experienced "acceptance" with being a survivor in the time lapsed post-injury. Carl, who was almost nine years post-injury, seemed somewhat neutral about his employment. Notably, Carl's wife explained that he had experienced a decrease in emotional expressiveness after his injury. The researcher determined from the interview that Carl clearly had no intention of resigning even at his advance age. Bob and Sara were both less than three years post-injury and were the least satisfied with their work statuses. Bob and Sara may simply require more time to acclimate to life as a survivor, in order to experience more contentment with their employment situations.

Another possible explanation for the discrepancy between job satisfaction and

PIES scores may be that those survivors with a higher quality of life in general, appear more satisfied with their work. Wade and Shelly seemed more fulfilled overall than Bob and Sara. Wade and Shelly had the most social interaction of the five survivors, which may have positively influenced their overall quality of life. Wade in particular, experienced a more active social life as well as support from family and friends. On the other hand, Bob was unemployed, did not seem to fill his pass time with hobbies or activities, and experienced social isolation as documented in his theme “*Chasing Cars.*” Sara admittedly did not spend time with friends and Carl’s wife Beth spoke about a change in their social interactions following Carl’s injury. On the other hand, Shelly’s mother spoke about how many friends Shelly had and Wade’s full social life was evident in his theme *Activities, social life, and support.*

### **Job Satisfaction**

Unemployed individuals report even less well-being than individuals experiencing other drastic life changes such as divorce (Clark & Oswald, 1994). Further, these researchers have shown that this dissatisfaction persists even with the receipt of government financial assistance (Clark & Oswald, 1994), suggesting that the discontentment results from a lack of work rather than a lack of income. For the survivors in this study, job satisfaction appeared to relate more to participating in a work or volunteer activity than to receiving pay for actual work performed. Of the five case study participants, Bob was clearly the least satisfied regarding work experiences. This was not surprising given that he only worked four months post-injury before his termination. The case study findings regarding Wade’s volunteer work combined with the cross-case

analyses provided further support for this point. Wade appeared to enjoy his volunteer work and had maintained his positions for five years, despite the fact that he did not receive pay.

Working, particularly at jobs that people find challenging, may contribute to increased self-esteem (Applebaum, 1992; Barnes, 1999; Kohn & Schooler, 1983). In terms of qualitative findings, Sara reported no longer feeling challenged by her work given the reduction of duties she experienced, which in turn made her dislike her job at times and feel “bored.” On the other hand, Shelly was very satisfied with her work, describing it as her “passion” despite citing frustrations with job tasks such as creating budgets.

Finally, researchers have documented that working increases the likelihood that individuals will create friendships (West, 1995) and employment factors relate to social aspects affecting a survivor’s quality of life and general well being (e.g., Finset, Dynes, Krogstad, & Berstad, 1995; Johnstone, Mount, & Schopp, 2003; O’Neil et al., 1998). In addition, the loss of employment competence can negatively affect a survivor’s self-identity, autonomy, and emotional well-being (Prigatano, 1989). Despite Wade’s lack of paid employment, he took pride in his volunteer duties and experienced satisfaction with his life in general. He enjoyed many different social activities and had several friendships. Similarly, Shelly’s mother, Gail, noted that she had “so many friends now.” These factors likely contributed to both survivors seemingly high quality of life. Contrarily, the lack of social interaction for Bob was readily apparent in his case study theme “*Chasing cars.*”

### ***Professional/Administrative Careers***

Many researchers (e.g., Boake et al., 2005; Dikmen et al., 1994; MacKenzie et al., 1998) have documented that survivors of brain injury with a higher pre-injury job status fare better with obtaining and maintaining employment post-injury than survivors with a lower pre-injury job status. Three of the five qualitative survivor participants held *professional/administrative* careers at the time of the interviews. Carl, Sara, and Shelly exemplified this point, as they each maintained a professional job for at least two years post-injury. Two of those survivors, Carl and Sara, returned to and maintained their pre-injury employment following injury. This counters the view that survivors may struggle more with these types of jobs, as they typically require higher-level cognitive skills and executive functioning than jobs in other fields.

Researchers (Boake et al., 2005) suggest that this occurrence may be due to increased flexibility with schedules and work tasks at this level of employment. Flexibility with both of these aspects is apparent in Carl and Sara's case studies. Beth assumed many of Carl's required job tasks, and Sara's co-workers assumed a few of her pre-injury duties upon her return. Carl scheduled his own hours, as he was self-employed and Sara noted that one of the benefits of her job was flexible afternoon hours. Shelly did not report similar flexibility in her job. This may have been because she had chosen a different career path at the time of her interview, many years post-injury, and had obtained her graduate degree after her injury. Carl and Sara, on the other hand, were comparing job duties from the same position they had held prior to injury as well as following injury. Because Carl, Sara, and Shelly had earned master's degrees, their

careers may have been more specialized, limiting their job competition

### **Level of Pre-injury Education**

Previous researchers have investigated survivors' levels of pre-injury education more often than any other variable in RTW studies. The majority of these researchers (i.e., Asikainen et al., 1996; Boake et al., 2005; Doctor et al., 2005; Franulic et al., 2004; Gollaher et al., 1998; Greenspan et al., 1996; MacKenzie et al., 1998; O'Neil et al., 1998; Sherer et al., 2002; Simpson, & Schmitter-Edgecombe, 2002; Wagner et al., 2002) concluded that the higher a survivor's pre-injury education level, the more likely he/she was to obtain employment post-injury. Walker and colleagues (2006) also found having a greater amount of pre-injury education increased the likelihood of a survivor holding either a professional or a managerial job. In the present study, Carl and Sara had attained higher levels of pre-injury education than the other survivors had, and they were the only survivors to maintain their pre-injury jobs post-injury. Carl, Sara, and Shelly—survivors with higher levels of education than Bob and Wade—held professional or managerial positions post-injury; Bob, when he was employed, and Wade held blue collar positions.

### **Modifications of Job Duties**

Survivors often benefit from using external aids to reduce the memory and cognitive demands placed on them (e.g., Sohlberg & Mateer, 2001). The survivors who were successful with obtaining and maintaining paying jobs following their injuries, namely Sara, Shelly, and Carl, implemented compensatory strategies and/or needed modifications to their job responsibilities. Sara and Shelly cited several examples of the strategies they used to ensure their success at work. The majority of these strategies

centered on compensating for memory problems and aiding organizational skills (e.g., note-taking and the use of planners and calendars). Wade also provided an example of a memory strategy he devised and implemented—specifically, keeping a list of duties in his wallet, so he did not forget what he needed to do—to ensure adequate performance of his volunteer work. The employment success of Sara, Shelly, and Wade likely was enhanced with such compensatory strategies. Carl, in contrast, was reluctant to use compensatory strategies, and this probably hampered his success, as reflected in his need for considerable support to complete his work responsibilities. In fact, Carl’s wife, Beth, assumed responsibility for performing several of his job tasks—such as completing paperwork and performing mathematical computations. Carl’s work supervisor even stated that if Beth had not “stepped in,” she likely would have had to fire Carl.

Survivors who are successful in resuming work post-injury sometimes need modifications to their job duties as well. In the present study, Sara provided examples of the job modifications she needed. Specifically, she could no longer travel to perform job-related activities, and she had to stop writing software specifications, both of which were tasks she had performed prior to injury. Sara also noted that only after injury did she require assistance with her demonstrations.

Shelly did not mention job task modifications. This aspect likely did not apply to her, as she had obtained her current employment many years post-injury. When speaking about returning to her pre-injury job, which she was fired from after returning for approximately 4 months, Shelly failed to mention any changes in her job duties or expectations or strategies she implemented to support her performance of specific job

responsibilities. The lack of modifications to tasks and possible failure to implement strategies may have contributed to Shelly's termination from her pre-injury position.

Bob used note-taking as a memory support strategy upon returning to his pre-injury job, though it clearly proved unsuccessful in helping maintain his position.

However, Bob did not mention job task modifications and, in fact, noted a complete change in job responsibilities. Placing a survivor of brain injury in a new position with new job duties is counterproductive, because new learning is one of the most difficult tasks for survivors (Ylvisaker et al., 2001). This fact likely contributed to Bob's failed attempt at returning to work and may have ultimately resulted in his termination.

### **Limitations**

Several limitations existed for this study. First, all data were derived from or about survivors with severe injuries, and, therefore, the results cannot be generalized to survivors with mild or moderate injuries. Second, despite the fact that all of the survivors had severe injuries, they had experienced good enough recoveries to return to work following their injuries. This fact may suggest that all or most survivors who experience severe injuries have the potential to return to work, which simply is not the case. Many survivors of severe injury remain in a state of impaired consciousness, experience a debilitating lack of mobility, or have cognitive impairments that make it implausible for them to work in either paid or unpaid positions.

Third, the researcher was unable to control for rehabilitation facility discharge outcomes for the survivor participants. Despite the fact that the 283 survivors from the database were discharged from the same rehabilitation facility, there was still no way for



the researcher to ensure that all of those survivors experienced similar levels of ability at their time of discharge. This fact is consistently a limitation of research with survivors of brain injury due to the individuality of each survivor and his/her specific challenges.

Next, the researcher acknowledges that both survivors and family members were self-selected. That is, all participants for this study, other than those represented in the database, chose to respond to the elicitation of research participation.

Another study limitation concerns the interpretation of qualitative results. The qualitative findings give a deeper understanding to the quantitative results using multiple case studies. Given the in-depth nature of qualitative findings, a small sample size is necessary. Therefore, one cannot generalize the findings to a larger population but should use them to understand the commonalities and differences among these particular survivors and associated participants. One must also interpret the quantitative results with caution, because the sample size was relatively small and mainly included survivors who had participated in rehabilitation at one particular facility.

### **Recommendations**

Consideration of the findings from this study lead to two specific recommendations for survivors regarding work following injury. First, when returning to work, survivors should implement strategies to aid them in compensating for their cognitive deficits. Short-term memory, particularly, is an area that commonly presents persisting challenges for survivors (West, 1995). Some strategies utilized by the participants in this study were the use of: (a) note-taking and lists; (b) calendars and planners (either conventional or electronic); (c) headphones to limit distractions; and (d)

support people in the survivor's life, such as friends, family members, and co-workers. Second, survivors should take part in productive activities. Specifically, if an individual cannot work due to physical or cognitive limitations, seeking a volunteer position is desirable. Simply the engagement in work activities, whether paid or unpaid, appears to improve a survivor's quality of life. Should a survivor fail in finding volunteer work, simply participating in structured, enjoyable activities may foster contentment (Csikszentmihalyi & LeFevre, 1989).

One of the survivors who participated in the qualitative portion of this study gave several recommendations for successfully working with survivors of brain injury. Shelly's first-hand experience with TBI and her work with others with disabilities prompted her to provide several suggestions regarding how employers can foster positive working relationships with survivors. Having flexibility and patience, being aware of imposing challenges, helping with self-awareness, and holding high expectations were among her recommendations:

Be flexible [with] them ... because this TBI individual needs someone who is willing to try and listen and be understanding and empathetic. Be patient ... with them, because they are not going to be able to find words. Don't find words for them. Give them challenges. ... That's going to work the brain [and] allow them to be more self-confident. If you find them to be sub-standard in certain areas, ... sit down and talk to them. ... Bring it to their awareness. They may or may not be aware. Give them a chance. ... Give them an opportunity. Decide what's priority. What does this

person have to necessarily do [correctly] to maintain their [sic] job and to do well?

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## APPENDIX A

## Telephone Interview

Hi! My name is \_\_\_\_\_. I am a researcher at UNL. You received a packet from us regarding a study we're conducting about survivors of TBI, and I received the consent form back from you. Is now a good time to talk? It should take between 10 and 20 minutes.

"No" When should I try back? \_\_\_\_\_

"Yes" Great!

Well, as was explained in the form we sent you we're trying to understand the post-injury work experiences of brain injury survivors. Because survivors often have memory problems we chose to talk to survivors' family members about some of the facts regarding their work history.

So the survivor in your life is named \_\_\_\_\_?

What is your relationship to \_\_\_\_\_?

1. What is (survivor's name)'s gender?      Male                      Female

2. What is (survivor's name)'s age? \_\_\_\_\_

3. What level of education did (survivor's name) have prior to injury? Choose one:

Did not finish high school	Highschool diploma/ GED	Some college
Associates degree	Bachelors degree	Graduate degree

4. Did (survivor's name) return to school after his/her injury? Yes                      No

If yes, did (survivor's name)'s earn a degree? Yes                      No

Current level of education:

Did not finish high school	Highschool diploma/ GED	Some college
Associates degree	Bachelors degree	Graduate degree

5. When did (survivor's name) have his/her injury? Month: \_\_\_\_\_ Year: \_\_\_\_\_

Briefly describe how (survivor's name)'s was injured: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

6. How many jobs did (survivor's name)'s have before injury (since completing his/her pre-injury education)? \_\_\_\_\_

7. Where did (survivor's name) work before his/her head injury? \_\_\_\_\_

---

P A T C O B Job Category (Circle one.)

What was (survivor's name)'s job title there? \_\_\_\_\_

How long did (survivor's name)'s work there? \_\_\_\_\_

1. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

2. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

3. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

4. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

5. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

Did he/ she do volunteer work prior to injury? Yes \_\_\_\_\_ No \_\_\_\_\_

8. Did (survivor's name) complete a vocational rehabilitation or any sort of work re-entry program after his/her injury? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, briefly describe: \_\_\_\_\_

9. Has (survivor's name) done any kind of paid or volunteer work since his/ her injury?

If yes, was it paid, volunteer, or both?: \_\_\_\_\_

List volunteer positions if applicable (Where? How many hours? Duties?):

List additional paid positions if applicable (Where? How many hours? Duties?):

9. What is (survivor's name)'s current employment standing? Choose one:

Unemployed

Volunteer  
(no pay)Paid Part-time  
(20 hrs/wk or less)Paid Full-time  
(more than 20 hrs/wk)**Complete either Section A or Section B:****Section A: If Survivor is employed:**

How many hours a week does (survivor's name) work? \_\_\_\_\_

Where is (survivor's name) employed? \_\_\_\_\_

P A T C O B Job Category (Circle one.)

What is (survivor's name)'s job title? \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

How long has (survivor's name) worked there? \_\_\_\_\_

Has (survivor's name) had any other jobs since his/ her injury? Yes

No

1. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

2. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

3. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

4. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

5. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

**Section B: If Survivor is unemployed:**

How long has (survivor's name) been unemployed? \_\_\_\_\_

What was (survivor's name)'s last job? \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long did (survivor's name) work there? \_\_\_\_\_

Has (survivor's name)'s had other jobs since his/her injury? Yes

No

1. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

2. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

3. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

4. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

5. Job title: \_\_\_\_\_

Briefly describe (survivor's name)'s job duties: \_\_\_\_\_

P A T C O B Job Category (Circle one.)

How long was (survivor's name) employed there? \_\_\_\_\_

Thank you again for your time. If we need more information or if we need to clarify some information is it okay to call you back?

We may be contacting you again, for study 2, to see if you and (survivor's name) would be willing to do a face-to-face interview in the future. Would that be okay? Yes No

## APPENDIX B

## Survivor Interview

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Participant's name: \_\_\_\_\_

Researcher's name: \_\_\_\_\_

Location: \_\_\_\_\_

1. Tell me how and when you sustained a TBI.
  - **Probe:** Were you hospitalized? Where?
  - **Probe:** How long?
  - **Probe:** How severe was the injury?
2. Tell me about any challenges you have experienced as a result of your TBI? Explain.
  - **Probe:** Cognitive challenges (e.g., memory, slowed information processing, impaired concentration/attention, organization, word-finding difficulty, etc.) resulting from the TBI.
  - **Probe:** Physical challenges (e.g., walking, balance, strength, coordination, tremors, etc.)? Explain.
  - **Probe:** Social-emotional challenges (e.g., mood swings, emotional lability, impulsivity, disinhibition, low frustration tolerance, verbosity, fatigue, etc.)? Explain.
3. Tell me about your work experiences before your injury?
  - **Probe:** Job titles
  - **Probe:** Job descriptions
  - **Probe:** Length of time at jobs
4. Tell me about your work experiences since your injury?
  - **Probe:** Job titles
  - **Probe:** Job descriptions
  - **Probe:** Length of time at jobs
5. What was the process like of getting your first job as a TBI survivor?
  - **Probe:** How did your boss/ supervisor/ manager respond to you when you were interviewing or first hired?
6. What is your current job and what are you required to do there?
7. What challenges resulting from the TBI interfere with job tasks?

8. What strategies do you use to help you with your job tasks (i.e., memory log/ book, extra communication with supervisor, accessibility of co-workers)?
9. What additional tools (i.e., planner, an additional schedule, visual aids) do you use to help you at work?
10. What factors (e.g., time of day, boss's instructional style, etc.) influence your job performance?
11. How well do you perform job duties compared to your co-workers?
12. How well do you perform job duties compared to before your injury?
13. In what ways, if any, did your boss, supervisors or co-workers change their interactions with you after finding out you were a TBI survivor?
14. How frequently do you have contact with your boss/ supervisor at work? Outside of work?
15. Did you complete a vocational rehabilitation program (other than your time at the rehab hospital) after your injury? Was it prior to getting hired at your current job? Explain.
  - What was that process like? Did you get help from any other services or agencies in obtaining your job?
  - Did rehab help you with job skills?
16. Did you enjoy your job before injury?
17. Do you enjoy your work now? (or did you enjoy it- when you were working after your injury)?
18. Any last thoughts you want to share?

## APPENDIX C

## Family Member Interview

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Participant's name: \_\_\_\_\_

Researcher's name: \_\_\_\_\_

Location: \_\_\_\_\_

1. Tell me how and when (TBI survivor's name) sustained a TBI.
  - **Probe:** Was he/she hospitalized?
  - **Probe:** How long?
  - **Probe:** How severe was the injury?
2. Tell me about any challenges (TBI survivor's name) experiences as a result of the TBI.
  - **Probe:** Cognitive challenges (e.g., memory, slowed information processing, impaired concentration/attention, organization, word-finding difficulty, etc.)?
  - **Probe:** Communication challenges?
  - **Probe:** Physical challenges (e.g., walking, balance, strength, coordination, tremors, etc.)?
  - **Probe:** Social-emotional challenges (e.g., mood swings, emotional lability, impulsivity, disinhibition, low frustration tolerance, verbosity, fatigue, etc.)? Explain.
3. What challenges resulting from the TBI interfere with work duties?
4. What strategies or techniques does (TBI survivor's name) use to help him/her perform on the job?
5. What additional tools does (TBI survivor's name) use to help succeed on the job?
6. How did (TBI survivor's name) obtain his/ her current employment?
7. What factors (e.g., time of day, instructional style, etc.) influence (TBI survivor's name)'s performance at work?
8. Are you involved in any way with (TBI survivor's name)'s job or communicate with his/ her work supervisors/ managers/ employer?
9. How do you support (TBI survivor's name)'s, in terms of his/her employment?

10. How has your involvement with (TBI survivor's name)'s employment changed over the years since the TBI?
11. What was (TBI survivor's name)'s employment before the injury like (job titles, duties, work stability, etc.)
12. How is (TBI survivor's name)'s current employment different from his/her past employment- both before and after the brain injury?
13. What are the major differences from then to now in for (TBI survivor's name)?
14. How has your role in (TBI survivor's name)'s life changed since his/her injury?



## APPENDIX D

## Work Supervisor Interview

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Participant's name: \_\_\_\_\_

Researcher's name: \_\_\_\_\_

Location: \_\_\_\_\_

1. What strategies or techniques does (TBI survivor's name) use to successfully complete job duties?
2. What is your knowledge base about TBI? How have you learned about it?
3. What type and frequency of communication do you have with (TBI survivor's name) at work? Outside of work?
4. In what ways, if any, does (TBI survivor's name) advocate for his/her needs at work?
5. How well does (TBI survivor's name) perform his/her job duties compared to other workers without disabilities? Other workers with disabilities?
6. At what job duties does (TBI survivor's name) perform best? What challenges have you noticed in terms of job duties?
7. What factors influence (TBI survivor's name)'s performance on job duties (i.e. time of day, fatigue, etc.)
8. In what ways do co-workers or other supervisors change the way they interact (negatively or positively) with (TBI survivor's name)?
9. What type and frequency of communication do you have with (TBI survivor's name) family members?
10. What information did you receive about (TBI survivor's name) before he/ she came to interview with you? Who gave you this information?
11. Are there any ways in which (TBI survivor's name) behaves differently socially than other employees during work? Explain.
12. How do your work expectations of (TBI survivor's name) differ from your expectations of other employees?